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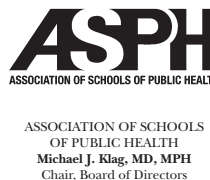
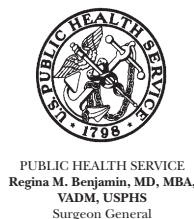
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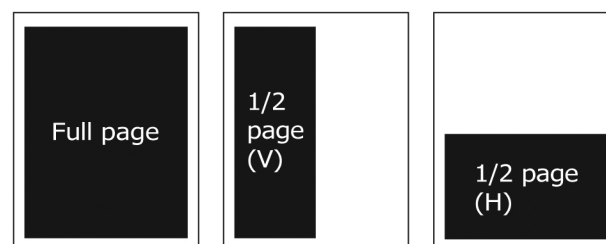
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# A Message from the Editor

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As I was preparing this message, I noticed a common theme among the articles. Normally, when selecting articles for a regular issue, we don't consciously group them according to topics; rather, we publish them in the order that they are approved during the review process. I suppose it was just serendipity that so many articles feature actions occurring at the state and local levels of public health.

Goodwin et al. describe a successful local effort to challenge Arizona legislation aimed at preventing adolescents from seeking treatment for sexually transmitted diseases (STDs) without parental consent. Jiang and colleagues used disability-adjusted life years to rank the burden of disease and injury in Rhode Island, and found that it produces a somewhat different picture of the state's disease and injury burden than does mortality-based ranking. Dwyer et al.'s report on the first eight years of a colorectal screening program in Maryland, which targets low-income, uninsured, medically underserved, and minority adults, identifies the program's strengths and weaknesses.

Three articles describe surveillance activities at the state and local level. Newman et al. examine how the STD surveillance network in five different cities and states identified two very different yet concurrent gonorrhea epidemics in minority populations. Bahraini and colleagues found high agreement between the use of the Colorado Violent Death Reporting System and the Veterans Affairs Beneficiary Identification Record Locator Subsystem to determine Veteran status among those who committed suicide. And Samoff et al. determined that integrating syndromic surveillance data into daily practice at local health departments in North Carolina has positive outcomes.

Each year, our nation remembers workers who died or sustained work-related injuries or illnesses during the previous year. This year, Workers Memorial Day falls on April 28. To recognize these workers and call attention to the importance of ensuring safe workplaces, *PHR* joins in this commemoration by publishing an article by Runyan et al. regarding the development of a research agenda to address safety issues for young workers.

Our special supplement to this issue, "Innovations in Oral Health Care for People Living with HIV/

AIDS," which focuses on a Special Project of National Significance (SPNS) funded by the Health Resources and Services Administration's HIV/AIDS Bureau, highlights the importance of program implementation and collaboration at the local level. Through the SPNS study, HIV-positive individuals who had not received any nonemergency dental care in the past year were given a variety of oral health-care services. The study encompassed 15 sites from around the country, about half in urban and half in rural communities. The research presented in this supplement shows that innovative program models can engage and retain those living with HIV/AIDS into oral health-care services. One notable result was that sites demonstrated effective collaboration among medical and dental providers as well as interdisciplinary teamwork within the dental profession, such as cooperative efforts by dentists, dental hygienists, and dental case managers at the local level. Findings from the study provide further evidence of the need for public health strategies to help patients understand that good oral health is necessary for overall health and well-being, particularly for vulnerable populations, such as those living with HIV/AIDS.

With this issue, we bid farewell to two long-term members of our Editorial Committee, Richard Clayton and Richard Henry. Dr. Clayton and CDR Henry have served admirably with *PHR* for many years by reviewing manuscript submissions and advising *PHR* Editors on editorial content. We thank them both for their dedicated service and wish them well as they pursue other endeavors. Their work with *PHR* over the years has been invaluable.

As we search for permanent Editorial Committee members, we welcome three colleagues who have agreed to temporarily join the team: Beth A. Resnick, MPH, of the Johns Hopkins Bloomberg School of Public Health; Zygmunt Dembek, PhD, of the U.S. Army Medical Research Institute for Infectious Diseases; and Russell Kirby, PhD, of the University of South Florida. All have been with *PHR* as consultants for several years, so we anticipate their transition to the Editorial Committee will be a smooth one.

Janice Huy  
Captain (Ret.), U.S. Public Health Service

# Surgeon General's Perspectives

## RAISING AWARENESS OF VIRAL HEPATITIS: NATIONAL HEPATITIS TESTING DAY, MAY 19

The first-annual National Hepatitis Testing Day is May 19, 2012. This action is a direct result of the report, “Combating the Silent Epidemic of Viral Hepatitis: Action Plan for the Prevention, Care and Treatment of Viral Hepatitis,” issued by the U.S. Department of Health and Human Services (HHS) in 2011.<sup>1</sup> Viral hepatitis is a silent epidemic in the United States that affects an estimated 5.3 million people. In fact, hepatitis B and hepatitis C are 3.5–5 times more prevalent than human immunodeficiency virus. Yet, the significance of viral hepatitis as a public health problem is underappreciated by both clinicians and the public. A recent Institute of Medicine report indicated a general lack of knowledge about viral hepatitis by health-care and social-service providers, people at increased risk of infection, and the general public. The report found this lack of knowledge to be a major obstacle to successfully preventing the liver diseases and cancer caused by these infections.<sup>2</sup>

Viral hepatitis can lead to cirrhosis, liver failure, and liver cancer, but infection is often silent and symptomless until the development of significant liver disease, which can occur years after the initial infection. As such, infection frequently goes undetected. Approximately one-third of people with chronic hepatitis B infection and three-quarters of people with chronic hepatitis C infection in the U.S. are unaware that they are infected.<sup>2</sup> Lack of knowledge of one's infection status means that people fail to seek needed care and treatment. This lack of treatment can lead to serious consequences, as 15%–25% of people with hepatitis B infection and an estimated 37% of people with hepatitis C infection will die as a result of their infection if they do not receive needed treatment.<sup>2,3</sup>

Fortunately, care and treatment can reduce the progression of liver disease caused by viral hepatitis. In many cases, treatment for hepatitis C can eliminate the virus from the system, essentially providing a cure. To help people living with viral hepatitis benefit from care and treatment, HHS has made viral hepatitis testing a national health priority. However, to increase testing, clinicians must first determine who should be tested.

In the U.S., an estimated 47%–70% of people with chronic hepatitis B are foreign-born. People born in Asia and Africa are at particular risk of having chronic hepatitis B infection due to the high prevalence of



VADM Regina M. Benjamin,  
Surgeon General

hepatitis B in their countries of origin.<sup>4</sup> This group represents a large patient population in the U.S., as 65% of Asian people living in the U.S. were born outside of the country, and 60% of new immigrants come from countries where hepatitis B is prevalent. This large burden of disease among a small population represents an important health disparity in the U.S. Clinicians can begin to identify people at risk of chronic hepatitis B infection by asking their patients two simple questions: (1) where were you born and (2) have you ever been tested for hepatitis B?

While foreign-born people comprise the majority of the chronic hepatitis B burden in the U.S., the traditional risk factor for hepatitis C infection is injection drug use. Estimates of hepatitis C infection among long-term injection drug users (IDUs) range from 65% to 90%.<sup>2</sup> Unique opportunities exist to test IDUs at substance abuse treatment facilities and syringe-exchange programs. African Americans, particularly African American males, are more likely to be infected with hepatitis C than the general public.<sup>5</sup> While injection drug use is a well-known risk factor for hepatitis C infection, data have suggested that, among all demographic groups, prevalence is highest among people born between 1945 and 1965; in other words, baby-boomers. Three out of four hepatitis C-infected people were born within this birth cohort,<sup>6</sup> likely due

to increased injection drug use and use of blood and blood products for transfusion, which caused hepatitis C incidence to increase steadily throughout the 1980s.<sup>7</sup>

The 2011 HHS action plan<sup>1</sup> outlined actions, based on scientific evidence and extensive real-world experience, that can serve as a roadmap for reaching Healthy People 2020 objectives (e.g., eliminating new cases of hepatitis B in children 2–18 years of age; increasing hepatitis B vaccination rates in young children, health-care personnel, IDUs, men who have sex with men, and hemodialysis patients; and reducing new hepatitis C infections from 0.3 to 0.2 per 100,000 population).<sup>8</sup> The action plan addresses six main areas: educating providers and communities; improving testing, care, and treatment; strengthening surveillance; eliminating vaccine-preventable hepatitis; reducing viral hepatitis caused by drug use; and protecting patients and workers from health-care-associated viral hepatitis.<sup>1</sup>

Additionally, to help the general public determine its risk of viral hepatitis infection, and to help clinicians determine their patients' risk of infection, the Centers for Disease Control and Prevention (CDC) is developing an interactive online risk-assessment tool. The tool will allow individuals to answer questions based upon CDC's guidelines for viral hepatitis testing and vaccination and will produce individualized recommendations, which can be printed and shared with a person's health-care provider. The risk-assessment tool is scheduled to be released in May.

Hepatitis is a hidden epidemic with significant public health consequences. National Hepatitis Testing Day is designed to raise awareness of one's hepatitis B and hepatitis C infection status. I encourage clinicians to take this opportunity to let their patients know about their risk of infection, explain the benefits of hepatitis B and C testing, and offer testing to those at risk.



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# Return of Epidemic Dengue in the United States: Implications for the Public Health Practitioner

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## ABSTRACT

Conditions that facilitate sustained dengue transmission exist in the United States, and outbreaks have occurred during the past decade in Texas, Hawaii, and Florida. More outbreaks can also be expected in years to come. To combat dengue, medical and public health practitioners in areas with mosquito vectors that are competent to transmit the virus must be aware of the threat of reemergent dengue, and the need for early reporting and control to reduce the impact of dengue outbreaks. Comprehensive dengue control includes human and vector surveillance, vector management programs, and community engagement efforts. Public health, medical, and vector-control communities must collaborate to prevent and control disease spread. Policy makers should understand the role of mosquito abatement and community engagement in the prevention and control of the disease.

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Dengue has traditionally been characterized as a neglected tropical disease that primarily affects populations in developing countries.<sup>1</sup> In recent decades, however, this disease has gained a new foothold in developed countries around the world, particularly those with subtropical regions, and now threatens the United States.<sup>2</sup> During the last 20 years, dengue outbreaks have occurred in Texas,<sup>3</sup> Hawaii,<sup>4</sup> and now in southern Florida.<sup>5</sup> These outbreaks have reaffirmed that the U.S. has the conditions for autochthonous (i.e., locally acquired) transmission of the dengue virus. Therefore, public health practitioners and clinicians should be alerted to possible cases among returning travelers and the threat of dengue reemerging in the U.S. in years to come.<sup>5</sup>

The reestablishment of dengue as a transmissible disease in the U.S. has significant implications for public health. We outline several public health imperatives for preventing, mitigating, and responding to dengue outbreaks. Specifically, our review highlights the unique aspects of recent dengue outbreaks in the U.S.; the role of vector management programs and their impact on controlling dengue spread; the principal signs, symptoms, and methods for diagnosis and confirmation of dengue illness; and the public health tools to help prevent and control dengue transmission.

## BACKGROUND

Dengue is the most common and fastest-spreading mosquito-borne virus in the world. In fact, there has been a 30-fold global increase in the incidence of dengue in the past 50 years,<sup>6</sup> with an estimated 50 million dengue infections now occurring each year.<sup>7</sup> The World Health Organization estimates that approximately two-fifths of the global population (about 2.5 billion people) live in areas where the natural and social environment support dengue transmission, and where competent mosquito vectors are present.<sup>8,9</sup>

Dengue is a *Flavivirus* that is associated with a spectrum of illnesses. There are four dengue virus serotypes—DEN-1, DEN-2, DEN-3, and DEN-4—the first three of which have been involved in recent outbreaks in the U.S. Notably, certain Asian genotypic strains within the DEN-2 serotype appear to be associated with more severe outbreaks and more severe disease, in terms of clinical symptoms and viremia, than are seen with other serotypes.<sup>10,11</sup> Human infection with one serotype conveys serotype-specific lifetime protective immunity. However, individuals infected subsequently with another serotype are at risk for more severe disease manifestations, including dengue hemorrhagic fever (DHF) and dengue shock syndrome (DSS).

These complications presumably result from virus interaction with preexisting dengue antibodies from an antecedent infection.<sup>8,12</sup> *Aedes* mosquito vectors are known to transmit the dengue virus, principally *Aedes aegypti* (*Ae. aegypti*) and *Aedes albopictus* (*Ae. albopictus*). *Ae. aegypti* is considered to be the more efficient vector for dengue.<sup>13</sup> In the U.S., *Ae. aegypti* is present in significant numbers in the southern states and along the Eastern Seaboard.<sup>14</sup> *Ae. albopictus* has a larger range in the U.S., which spans the South, the East Coast, and the Mississippi River Delta (Figure 1).<sup>15,16</sup>

## DENGUE IN THE AMERICAS: BRIEF HISTORY AND THE ROLE OF *AE. AEGYPTI* ERADICATION

### Dengue pre-1850

Although dengue virus was not isolated until 1945,<sup>17</sup> epidemiologic and clinical reports are consistent with the occurrence of dengue epidemics in larger U.S. cities, as far back as Colonial times. In 1780, a dengue-like outbreak was reported in Philadelphia, Pennsylvania, and in the 1820s, dengue outbreaks also occurred in Pensacola, Florida; Charleston, South Carolina; Savannah, Georgia; and New Orleans, Louisiana.<sup>18</sup>

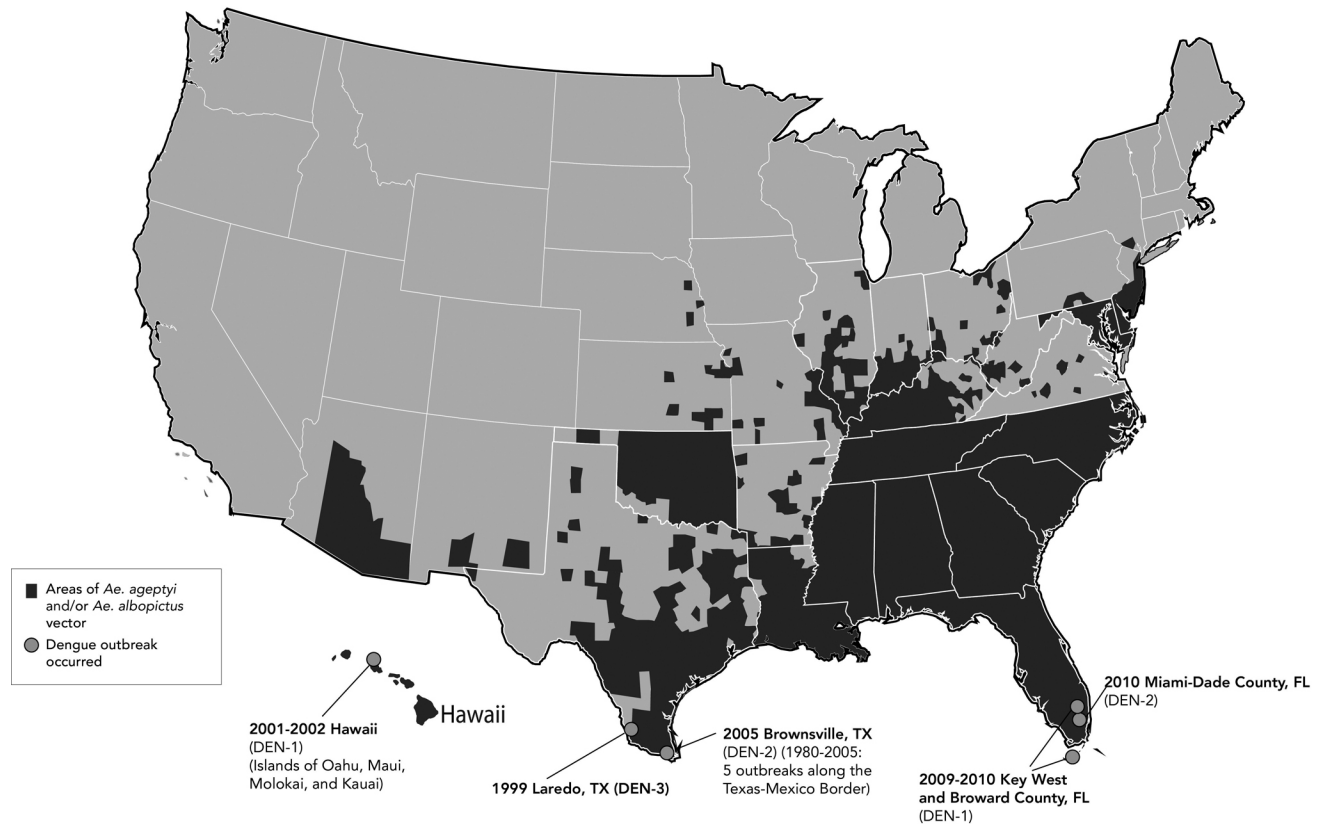
### Dengue: 1850–1945

During this period, dengue epidemics—some with tens of thousands of reported cases—occurred every few years in the southern U.S. In the late 1800s, the mosquito vector theory of disease showed that mosquitoes transmitted infections such as filariasis, malaria, and yellow fever. Mosquito-control programs, which began early in the 1900s in Havana, Cuba, and the Panama Canal Zone and later extended to most of Latin America, led to the virtual elimination of endemic yellow fever. These programs focused on reducing breeding habitats and killing larvae in containers, installing adequate sewage systems, fumigating via pesticides to kill adult mosquitoes, and clinical screening for the disease. In addition to these methods, later programs also successfully incorporated the use of dichlorodiphenyltrichloroethane (DDT). Successes in controlling yellow fever through mosquito-control programs led to a marked decrease in the incidence of dengue.<sup>19,20</sup>

### Dengue following World War II

The *Ae. aegypti* eradication program established by the Pan American Health Organization in the 1940s and 1950s to combat yellow fever was one of the most important factors in suppressing dengue in the U.S. through the 1970s.<sup>19,20</sup> A reemergence of dengue infections in the Americas was evident in the 1980s with the occurrence of major epidemics of dengue in



**Figure 1. Dengue vector populations (2009) and locally acquired disease in the United States (1980–2010)<sup>a</sup>**

<sup>a</sup>Areas marked in black indicate counties where mosquito surveillance has shown the presence of *Ae. albopictus* and/or *Ae. aegypti*. These areas are vulnerable to dengue outbreaks. Unmarked areas do not necessarily indicate the absence of the vector, as, in some areas, this may be the result of limited surveillance. Information on mosquito populations used for this map is from the Centers for Disease Control and Prevention's ArboNet and Exotic Vectors database data, as compiled for 2009 by Dr. Chet Moore, Colorado State University. Reference: Moore C. Reported distribution of exotic vectors in the U.S., 2009. Fort Collins (CO): Colorado State University; 2010.

*Ae. aegypti* = *Aedes aegypti*

*Ae. albopictus* = *Aedes albopictus*

DEN = dengue

CDC = Centers for Disease Control and Prevention

countries that had been dengue-free for 35 years or longer.<sup>13,21,22</sup> Several factors were associated with the expanded presence of dengue in the Americas at that time. First, the rapid increase in urban population density and vector breeding habitats provided ideal conditions for more widespread virus transmission. Second, support for mosquito-control programs waned, DDT use was banned, and mosquito control shifted to less effective methods, such as space spraying. Finally, increased globalization and travel led to the global movement of different dengue serotypes, and increased the opportunity for dengue to be introduced into susceptible areas.<sup>13,21–23</sup> Dengue outbreaks have occurred throughout the Americas since the 1980s; however, the U.S. has only seen sporadic outbreaks, primarily along the U.S.-Mexico border.

### Recent epidemics in the U.S.

In the past 60 years, the majority of cases reported in the U.S. have been imported, travel-associated infections in individuals returning from foreign endemic areas.<sup>24</sup> Case reports suggest that there are approximately 100 imported cases to the U.S. each year. Continually increasing international travel in recent decades, particularly to dengue-endemic areas, has increased the threat of dengue to the U.S.<sup>25</sup> In addition to travel-associated cases, a few notable dengue outbreaks involving autochthonous transmission have occurred in the U.S., while mosquito-control efforts have decreased in many parts of the country.

**Hawaii, 2001–2002.** In September 2001, the Hawaii Department of Health was notified of a suspect case

of autochthonous transmission, which was later confirmed by laboratory diagnosis. During the course of the outbreak investigation, 1,644 suspected cases were evaluated, and 122 cases of dengue were confirmed. While this outbreak was relatively small, the epidemic is notable for three reasons: (1) the 2001–2002 dengue epidemic was the first known occurrence of autochthonous transmission in Hawaii since 1944; (2) the vector responsible for the outbreak was *Ae. albopictus*, demonstrating this vector's competence in sustaining an epidemic in the absence of *Ae. aegypti*; and (3) it highlighted the vulnerability to dengue reintroduction of a susceptible population, in the setting of increasing circulation of the virus in the Pacific Basin region.<sup>4</sup> In the spring of 2011, the Hawaii State Department of Health began investigating two confirmed and two suspected cases of autochthonous transmission.<sup>26</sup>

**Brownsville, Texas, 2005.** Dengue activity in southern Texas demonstrates the significance of both imported cases from adjacent Mexico and the risk of rapid establishment of local transmission after importation of the virus. Limited outbreaks of locally acquired dengue have occurred sporadically in Texas along the border with Mexico since 1980.<sup>27</sup>

In summer 2005, the city of Brownsville, Texas, confirmed three cases of autochthonous dengue and 24 cases of dengue in people who had traveled to Mexico. It was part of a much larger epidemic that included 1,251 cases of dengue in the bordering Mexican city of Matamoros. What was most significant about this outbreak was the number of severe cases of dengue (DHF) that occurred in Matamoros, where 17.8% of the 1,251 confirmed cases were DHF. However, during the preceding four years, only 3.7% of dengue cases in that region of Mexico had been classified as DHF.<sup>3</sup> Reasons for the differences in the severity of disease between Brownsville and Matamoros are speculative but may be due to the introduction of a more virulent genotype of DEN-2.<sup>28</sup> Residents of both cities cross the border frequently, and the mosquito burden in the two locations is similar. However, living and working conditions differ between the two cities.<sup>29</sup>

Dengue remains an ongoing threat to southern Texas; prevalence of immunoglobulin (IgG) antibody to dengue was 38% in a randomly selected cohort of 800 adults in Cameron County on the Texas-Mexico border. People born in Mexico had statistically significantly higher antibody prevalence compared with those born in the U.S.<sup>30</sup>

**South Florida, 2009–2010.** In 2009 and 2010, Florida experienced its first documented cases of autochtho-

nous dengue since 1946. The first case, recognized in a woman who had traveled to Monroe County, Florida, was identified in September 2009. Subsequent investigation led to recognition of an outbreak in the Key West area of Monroe County. In 2009, 29 cases of locally acquired dengue were confirmed in Key West, and a serosurvey revealed that approximately 5% of Key West residents had been recently infected with dengue.<sup>5</sup> During 2010, 67 cases of locally acquired dengue had been reported: 65 cases were in Key West, and one case each occurred in Broward County and in Miami-Dade County.<sup>31</sup> As of the end of 2011, there were two locally acquired cases each in Miami-Dade and Palm Beach counties, and one case each in Hillsborough and Martin counties.<sup>32</sup>

## EVALUATION, DIAGNOSIS, CONFIRMATION, AND TREATMENT OF DENGUE ILLNESS

In 2010, dengue was added to the list of Nationally Notifiable Infectious Conditions,<sup>33</sup> signaling national concern about this public health threat and recognition by CDC of the need for increased surveillance and reporting. State reporting of dengue to CDC is voluntary. The presence of a non-travel-associated case of dengue should alert local public health authorities to the possible existence of an outbreak. Health-care providers also need to be alerted to this possibility. They should understand the spectrum of dengue illness, the importance of obtaining confirmatory specimens, and the process for reporting suspect cases of dengue.

### Signs and symptoms of dengue illness

Of those experiencing their first dengue infection, children are more likely to be asymptomatic, and adults are more likely to be symptomatic. Most people with symptomatic illness will have uncomplicated dengue infection, presenting as undifferentiated fever or dengue fever. Severe dengue, seen in few infected people, manifests as DHF or DSS.

**Classic dengue fever.** People with classic dengue fever typically begin experiencing influenza-like symptoms about four to seven days after the infecting mosquito bite. Symptoms include joint pain, prostration, musculoskeletal pain, nausea, vomiting, and rash. Approximately three to four days into symptomatic illness, fever dissipates but may recur, giving the illness a biphasic or “saddleback” fever pattern. Hepatitis may also complicate the illness.<sup>34</sup> Current treatment for those with dengue fever is supportive care. Hemorrhagic manifestations, such as petechiae or gum bleeding, may also be seen in some patients.

**Figure 2. Case classification for potential dengue cases<sup>a</sup>**

| Disease case classification | Definition                                                                                                 |
|-----------------------------|------------------------------------------------------------------------------------------------------------|
| Suspect                     | A clinically compatible case of dengue illness that is epidemiologically linked to a confirmed case        |
| Probable                    | A clinically compatible case of dengue illness with laboratory results indicative of presumptive infection |
| Confirmed                   | A clinically compatible case of dengue illness with confirmatory laboratory results                        |

<sup>a</sup>Adapted from the Council of State and Territorial Epidemiologists' resource on Dengue Virus Infections in the Nationally Notifiable Conditions List, which is available from: URL: <http://www.cste.org/ps2009/09-ID-19.pdf>

**Severe dengue: DHF and DSS.** Severe dengue is mostly seen in people who are infected with a second dengue serotype, after having experienced a different dengue serotype infection at some time in the past. Infants with maternal antibodies to dengue are also at risk.<sup>35</sup> Patients with DHF experience the same symptoms as those with classic dengue fever, but at defervescence exhibit hemorrhagic manifestations and evidence of plasma leakage shown by hemoconcentration and pleural effusions. Approximately 20%–30% of patients with DHF will progress to DSS, the most severe form of the disease, with shock and severe swelling due to capillary leakage.<sup>36</sup> The early course of illness for both DHF and DSS is indistinguishable from classic dengue fever, and both DHF and DSS manifest following resolution of fever.<sup>34</sup> Vigorous supportive treatment, including strict attention to fluid and electrolyte balance, is the only available treatment and can reduce mortality to as low as 1% (Figure 2).<sup>8</sup>

### Confirmatory diagnosis of dengue

When dengue fever is suspected, laboratory confirmation of illness is necessary to provide a diagnosis and prognosis, and to allow for public health reporting. As shown in Figure 3, several relatively simple steps are necessary to confirm diagnosis.<sup>37</sup>

Three approved and commonly used clinical diagnostic tests are available in the U.S. for dengue: real-time polymerase chain reaction (RT-PCR), immunoglobulin M (IgM) antibody capture enzyme-linked immunosorbent assay (MAC-ELISA), and IgG ELISA. Culture of the virus has largely been supplanted by RT-PCR methods. However, due to the natural history of dengue infection, many patients come to medical attention after the viremic phase of illness (i.e., the first five days of illness) when PCR may be negative,

leaving serologic assays as the chief means of diagnosis. The standards for serological analysis, IgM and IgG ELISA testing of blood, are the preferred and highly sensitive means of diagnosis.<sup>34</sup> As shown in Figure 4, ELISA testing can require up to three days for completion and should be performed after six days of illness have passed.<sup>38</sup>

### Role of early recognition

Early detection and knowledge of illness, timely reporting, confirmation, and rapid response are vital in dengue control.<sup>39,40</sup> Because no specific antiviral treatment or vaccine is available, management of dengue outbreaks relies primarily on vector control. Health departments will require time to scale up vector-control activities, and the more lead time they have, the more efficacious the measures will be. Finally, early recognition allows for more timely communication with the public, which is important.

## PROPOSED PUBLIC HEALTH TOOLS FOR MITIGATION OF DENGUE

Public health practitioners should have capabilities in place to recognize and respond to dengue outbreaks, control of which largely depends on disease surveillance, clinician awareness, and mosquito vector control. After identification of an outbreak, the following interventions are needed.

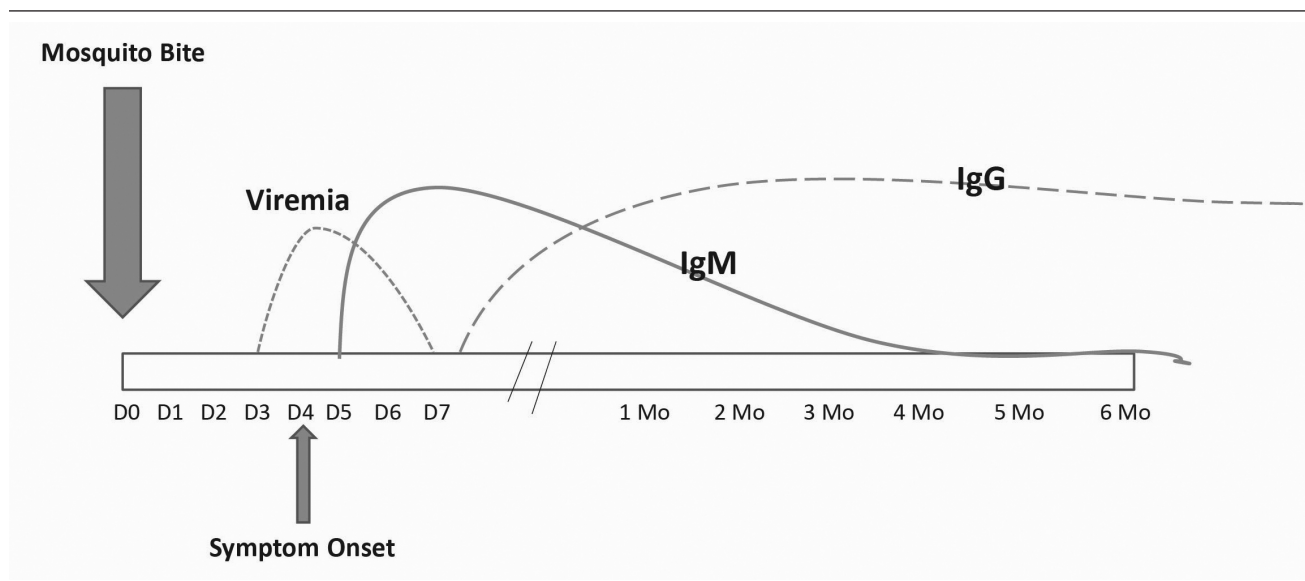
### Figure 3. Testing<sup>a</sup> for dengue infection in suspect patients

- Step 1: Obtain blood specimens from suspect patient to confirm infection.
  - First 5 days of illness: First blood sample.
  - 14–21 days after onset of illness: Second blood sample.
  - Note: If a patient is seen more than five days after onset of illness, only a single sample is needed.
- Step 2: Test of blood specimens for antibodies to dengue or the presence of the virus nucleic acid signatures by PCR.
  - ≤5 days after onset of illness: PCR is likely to be positive (definitive diagnosis).
  - >5 days after beginning of symptoms: IgM antibodies that indicate recent exposure will be present (presumptive diagnosis).
- Step 3: Notify local health authorities.

<sup>a</sup>Tests may be offered by a hospital or reference laboratory (e.g., Quest, LabCorp, Mayo Clinic, or a university), a local/state health department, or the Centers for Disease Control and Prevention. The processing of samples for serologic diagnosis takes approximately one week, and for PCR results, approximately three days. For information as to where specimens should be sent, providers should contact state or local health departments.

PCR = polymerase chain reaction

IgM = immunoglobulin M

**Figure 4. Time course of dengue infection**

IgM = immunoglobulin M

IgG = immunoglobulin G

D = day

Mo = month

**Vector control and surveillance**

Mitigation efforts have played significant roles in controlling dengue outbreaks and will continue to do so even when a vaccine becomes available. Mosquito-control programs for dengue and other mosquito-borne diseases exist in a variety of forms in the U.S. Some mosquito-control programs are stand-alone programs without government funding, while others may be part of state or local public health, animal control, or environmental health departments. CDC provides additional expertise and guidance for state and local vector-control programs.

Successful control of dengue vectors is difficult to achieve and even more challenging to maintain. Vector-control programs work to control mosquito populations through pesticide spraying to kill adult mosquitoes, elimination of breeding habitats, and water management; the use of larvicides to kill mosquitoes in the larval stage; and the provision of biological controls, such as mosquito-eating fish.<sup>41</sup> Mosquito-control programs use surveillance and sampling to determine the extent of mosquito populations and to measure the impact of mosquito-reduction campaigns.<sup>19</sup>

**Community engagement**

Community engagement in areas that are vulnerable to dengue is a vital part of vector control, surveillance, reporting, and response to an outbreak. Community engagement is especially important to reduce mosquito

breeding on privately owned property and to sustain a long-term program.<sup>22</sup> Communication campaigns and outreach may be necessary to improve public understanding of why they should support mosquito control, the dangers of dengue, and the consequences of allowing mosquitoes to breed around their homes. Without this public-private partnership in the control of dengue vectors, mosquito-control programs are unlikely to successfully prevent or control dengue outbreaks.

Engagement of the clinical community in areas that are susceptible to dengue is critically important. Clinicians should be educated and informed about the status of the disease in their area, so that they will be aware and more likely to diagnose cases of dengue. Public health authorities can help inform clinicians by providing a case definition and frequent updates about any dengue activity in their jurisdiction.

**Candidate vaccines**

The U.S. Food and Drug Administration has not licensed a dengue vaccine. However, three promising candidate vaccines are currently in clinical trials. All candidate vaccines are live attenuated tetravalent formulations that are being developed separately by Sanofi Pasteur, GlaxoSmithKline, and the National Institutes of Health. Dengue vaccines have been difficult to develop because of concerns about the occurrence of DHF/DSS in individuals who may be exposed to a dengue virus after being vaccinated but before



the tetravalent virus immunity is achieved following immunization.<sup>42</sup> Although current vaccine development efforts are aimed at endemic area populations outside the U.S., if licensure were sought in the U.S., a tetravalent dengue vaccine would likely be recommended for all travelers to endemic areas. Domestic use of such a vaccine would likely be reserved for locations where endemic transmission was identified (Figure 5).

## CONCLUSIONS

Dengue has traditionally been categorized as a neglected tropical disease not frequently associated with the U.S. However, recent dengue activity in the U.S. demonstrates that areas of the country are at risk of experiencing outbreaks. Practitioners in areas with dengue mosquito vector species should be aware of the risk of imported dengue resulting in an outbreak. The risk for dengue outbreaks is steadily increasing as the result of changing demographics and increases in international travel to dengue endemic regions.

### Figure 5. Key messages for U.S. public health practitioners regarding dengue infection

- Increasingly frequent introductions of dengue are occurring in the U.S. in areas with *Aedes albopictus* and/or *Aedes aegypti* mosquitoes, thus heightening the possibility of local epidemics and endemic foci. Public health practitioners in areas where these vectors are present should be aware of the dengue threat.
- In areas vulnerable to dengue, patients and health-care providers should be educated about the signs and symptoms of dengue. Medical providers should be encouraged to obtain specimens and report cases.
- The presence of multiple serotypes and newly introduced genotypes of dengue is a cause for concern and may lead to increased incidence of severe dengue (dengue hemorrhagic fever and dengue shock syndrome) in the U.S.
- Policy makers should understand the critical role of vector control and allocate funds for this activity according to the risks they face for dengue outbreaks.
- States that are at risk for dengue and those that have had outbreaks should strengthen disease surveillance for dengue, including both human disease surveillance and vector surveillance.
- Health departments in areas at risk for dengue should strengthen collaboration with mosquito-abatement districts to identify risks to local communities and to exchange information and data.
- Travelers from dengue endemic areas with fever within two weeks of return should have dengue considered in the diagnosis.
- Public health departments and mosquito-control agencies should prioritize public communication and community engagement for reducing mosquito populations and recognizing and reporting possible cases.

To prevent and mitigate the impacts of dengue, early investments are needed to detect outbreaks and limit spread. Public health practitioners must be alerted to the possible occurrence of dengue in the population and engage with the public to increase awareness about dengue. Clinicians must be aware of dengue as a possible diagnosis for patients with a febrile illness during the summer and autumn, when mosquitoes are most prevalent. Vector-control agencies should increase their investments in mosquito control to prevent and respond to dengue and other mosquito-borne diseases.

Dengue has the potential to reemerge as a public health threat in many areas of the U.S., and dengue outbreaks could have severe health and economic consequences. Many vulnerable communities are not aware of the risk, which is why public health practitioners play a key role in raising community awareness and also establishing robust prevention, mitigation, and response efforts for this threat.

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# From SARS to 2009 H1N1 Influenza: The Evolution of a Public Health Incident Management System at CDC

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## ABSTRACT

The organization of the response to infectious disease outbreaks by public health agencies at the federal, state, and local levels has historically been based on traditional public health functions (e.g., epidemiology, surveillance, laboratory, infection control, and health communications). Federal guidance has established a framework for the management of domestic incidents, including public health emergencies. Therefore, public health agencies have had to find a way to incorporate traditional public health functions into the common response framework of the National Incident Management System. One solution is the development of a Science Section, containing public health functions, that is equivalent to the traditional incident command system sections. Public health agencies experiencing difficulties in developing incident management systems should consider the feasibility and suitability of creating a Science Section to allow a more seamless and effective coordination of a public health response, while remaining consistent with current federal guidance.

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At the Centers for Disease Control and Prevention (CDC), the response to public health emergencies, including infectious disease outbreaks, has historically been organized according to traditional public health functions, such as epidemiology, surveillance, laboratory, infection control, and health communications. Guidance from the Department of Homeland Security<sup>1</sup> and directives from the White House (e.g., Homeland Security Presidential Directives)<sup>2,3</sup> have established an approach for organizing and managing emergency responses through a common framework, the National Incident Management System (NIMS). As a result, CDC and other public health agencies are adapting their emergency response operations to comply with this guidance and improve their response to infectious disease outbreaks and other public health emergencies. The integration of public health response functions with the principles of emergency management (i.e., NIMS) requires a balanced approach. Although public health must abide by the response architecture outlined in NIMS, it is important to ensure that the implementation of a common framework enhances, rather than encumbers, the ability of public health practitioners to perform traditional public health response activities.

In response to the federal guidance, CDC developed a compatible incident management system (IMS) to manage the agency's response to public health emergencies. However, this organizational structure was difficult to implement because traditional public health response functions are not easily located within an IMS based on the principles of the Incident Command System (ICS). We describe CDC's challenges and solutions for including traditional public health response functions within the management structure. This discussion may assist other public health agencies that are struggling to identify and incorporate traditional public health functions within an incident management structure, based on current federal guidance.

### PRE-IMS: A TEAM APPROACH

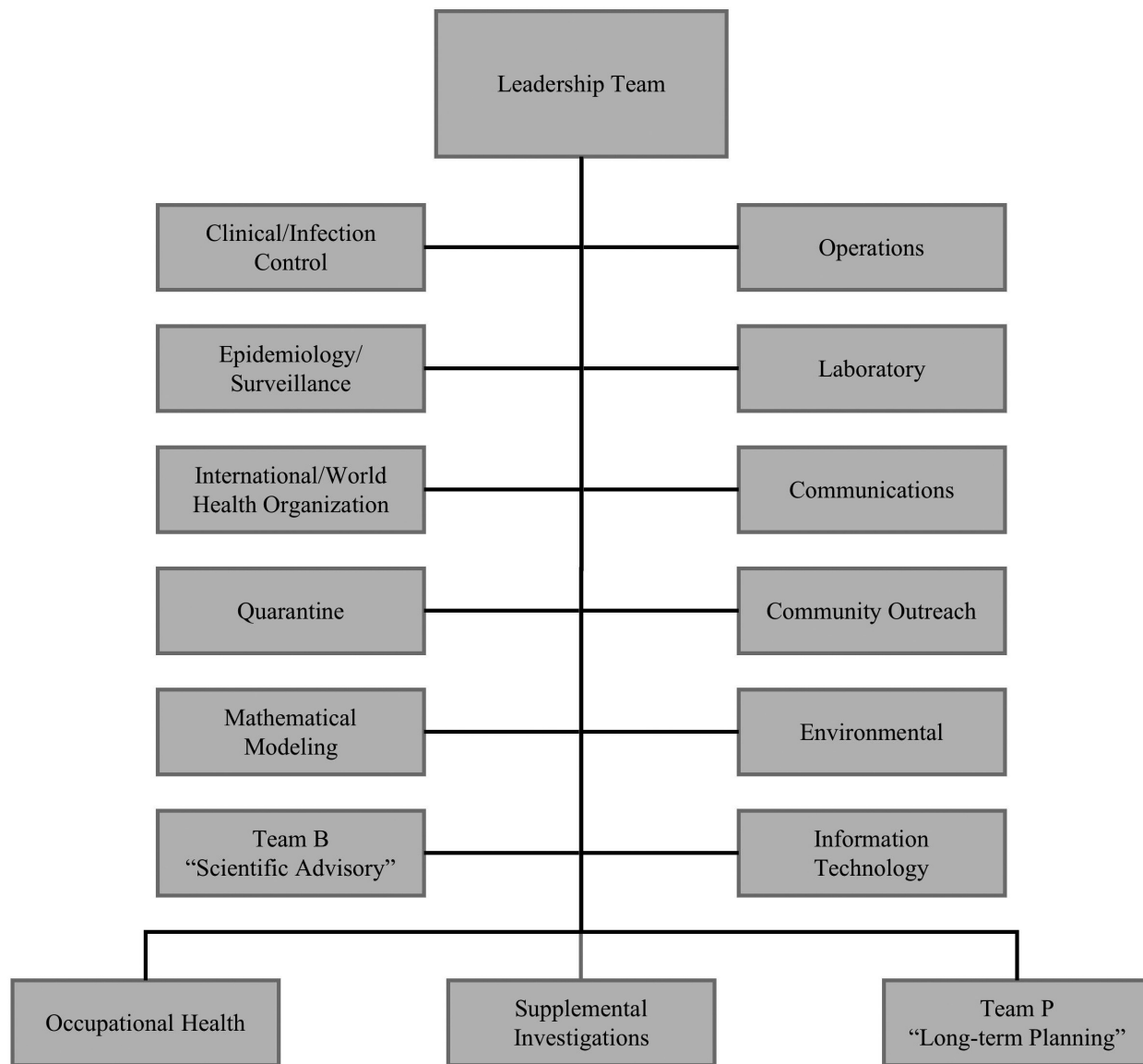
In 2003, NIMS was being developed in an attempt to standardize the management of domestic incidents by creating a single, comprehensive IMS.<sup>2</sup> At this time, CDC became involved with the public health response to the 2003 outbreak of severe acute respiratory syndrome (SARS). Because NIMS was still a draft document, the principles of ICS and incident management were not explicitly cited as the basis for establishing CDC's response structure during the SARS outbreak.<sup>4</sup> Instead, Posid et al.<sup>4</sup> noted that the 2003 SARS response used the "team" concept (Figure 1) to organize agency-wide response operations; the term "team" referred

to a group of people with complementary skill sets assembled to address a specific public health issue or fulfill a specific mission. During the SARS outbreak, the size, composition, and duration of the scientific/technical teams (e.g., epidemiology/surveillance, quarantine, and clinical/infection control), as well as other supporting teams (e.g., operations and information technology), were determined by the outbreak's evolving characteristics. Although the titles and labels of these teams were modified based upon incident-specific circumstances, the traditional public health functions performed by these core scientific/technical teams were essential to the agency's response to the SARS outbreak.

Following the response to the SARS outbreak, Posid et al. highlighted lessons learned that, if adopted, might better prepare CDC to more efficiently respond to future infectious disease outbreaks. One of those lessons was to modify an incident management structure that would be applicable for the response to large-scale infectious disease outbreaks. The response to the 2003 SARS outbreak "marked the first use of a newly established emergency operations facility and staff specifically hired to assist and support the CDC's response to a public health emergency."<sup>4</sup> As a result, CDC needed to develop a better system for integrating traditional public health response functions with the newly created infrastructure and programs designed to coordinate agency preparedness and response. Following the response to the 2003 SARS outbreak, CDC began to transition away from the team concept for the organization of response activities. In its place, CDC developed and implemented an IMS, which was consistent with proposed federal guidance and, in theory, allowed for a scalable and flexible approach for managing all activities, including the traditional public health response functions, during the response to a public health emergency.

### CDC IMS: INITIAL DEVELOPMENT

The response to a public health emergency, including infectious disease outbreaks, occurs at the state and local level. During a response, CDC assists state and local health authorities by providing scientific/technical guidance on agent- or event-specific issues or personnel to assist with field activities (e.g., case interviews or environmental sampling). Response activities may be program-centric (i.e., conducted within a single CDC program) or require the use of agency-wide resources. While many responses can be managed from within a CDC program, certain public health emergencies (e.g., Hurricane Katrina and 2009

**Figure 1. CDC organizational structure for the response to the 2003 SARS outbreak, using the team concept<sup>a</sup>**

<sup>a</sup>The term "team" refers to a group of people with complementary skill sets assembled to address a specific public health issue or fulfill a specific mission. During the SARS outbreak, the size, composition, and duration of the scientific/technical teams (e.g., epidemiology/surveillance, quarantine, and clinical/infection control), as well as other supporting teams (e.g., operations and information technology), were determined by the evolving characteristics of the outbreak.

CDC = Centers for Disease Control and Prevention

SARS = severe acute respiratory syndrome

H1N1 influenza) require an agency-wide response with a centralized management structure. For these agency-wide responses, CDC manages its response activities from a central location, the CDC Emergency Operations Center (EOC). The CDC EOC is designed to provide a focal point for coordinating and supporting staff, information, communication, and security issues associated with an agency-wide response. Once

activated, the CDC EOC uses an IMS organized by ICS section (i.e., Operations, Planning, Logistics, and Finance/Administration) rather than discipline or emergency support function. The ICS model allows CDC to be consistent with the management structure used by the operations center at the Department of Health and Human Services. Additionally, an ICS-based management structure allows CDC personnel deployed

to the field to be familiar with ICS concepts and principles, which are being used for on-scene response coordination at the state and local levels.

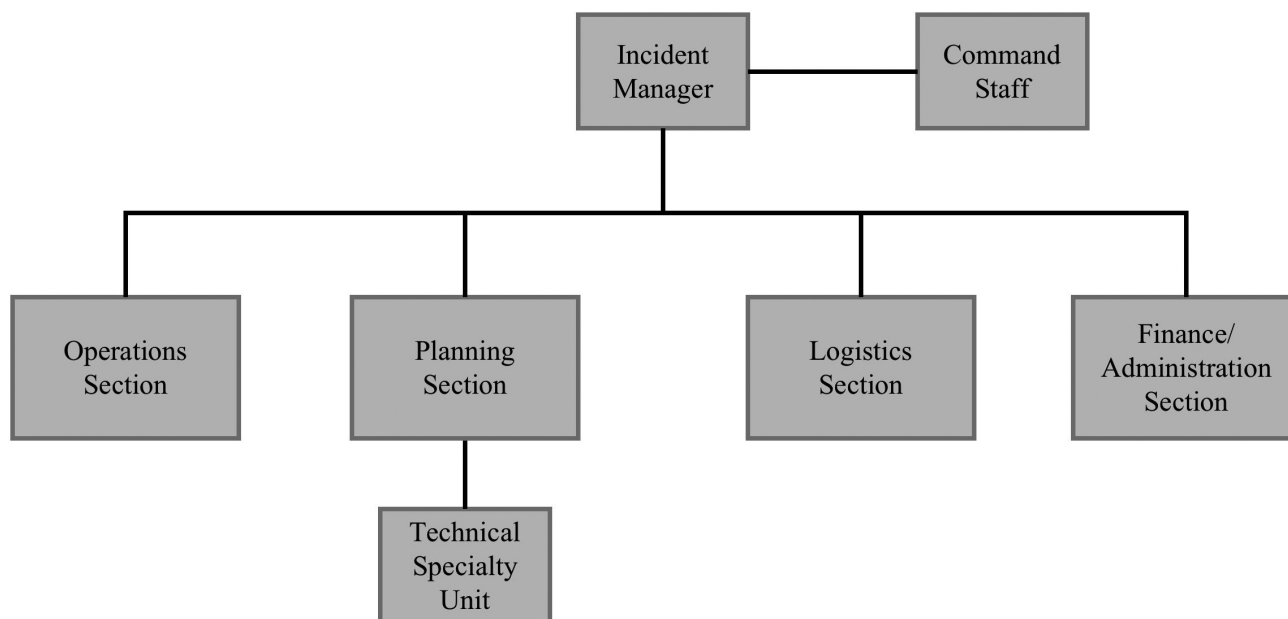
However, there are some challenges with organizing and managing a public health response according to the principles of emergency management. For example, although the response to an infectious disease outbreak is conducted in the field, the management or command of the investigation usually occurs at a centralized location. This centralization allows for the integration and coordination of multiple population-focused activities, which are based on traditional public health functions. Because the management of a public health incident occurs at a central location rather than in the field, the organization of response activities based on the principles and practices of on-scene incident command may be difficult to implement. For example, which ICS section should contain the traditional public health functions? Because the public health response involves both elements of operations and planning, initial attempts were made to split the management of the scientific and technical teams between the Operations and Planning Sections. Although this division may have been consistent with the principles of ICS, it could not effectively manage the public health functions. Because public health operations and planning activities are intertwined, it became difficult for CDC

responders to separate the team activities between the two sections. Adding to this confusion, the same name (e.g., epidemiology) was used to identify the teams in both the Operations and Planning Sections, which resulted in confusion and redundancies related to information flow through the CDC IMS. Therefore, an alternate approach was required to manage the public health functions within the CDC IMS.

### CDC IMS: TECHNICAL SPECIALTY UNIT

In 2005, CDC implemented a revised all-hazard IMS structure (Figure 2) that was based on the agency's lessons learned from the response to the 2005 hurricane season, which included hurricanes Katrina, Rita, and Wilma. This version of the CDC IMS still comprised four sections (Operations, Planning, Logistics, and Finance/Administration) and included numerous command staff positions. The Incident Manager position and other senior response leadership positions were staffed by subject-matter experts (SMEs) at CDC. Personnel from throughout the agency comprised the various technical and general staff positions. The scientific and technical teams, which still served as the foundation of the agency's response to a public health emergency, were organized into a unit within the Planning Section. This unit, called the Technical

**Figure 2. All-hazards CDC incident management system organizational structure, using a Technical Specialty Unit, based on lessons learned from the response to the 2005 hurricane season**



CDC = Centers for Disease Control and Prevention

Specialty Unit (TSU), was responsible for coordinating the activities associated with a public health response. The rationale for locating the TSU within the Planning Section was the need to link the public health response activities with the Incident Action Plan (IAP). Because the IAP captures the current and future activities of a response, associating the TSU with the Planning Section, which is responsible for developing the IAP, was thought to be beneficial. However, organizing and implementing a public health response on the basis of the TSU model also proved to be difficult.

Although the TSU was responsible for collecting and analyzing situational data for use in determining CDC's course of action, it was also responsible for coordinating and interacting with assets deployed in the field, developing scientifically accurate public health guidance, and working with partners to implement specific programs or strategies (e.g., sentinel surveillance and medical countermeasure distribution) to respond to the event. Therefore, the TSU was a hybrid of functions normally contained within the Operations and Planning Sections, making it difficult to solely locate the TSU within a single ICS section. This problem became more apparent as SMEs, who normally conduct infectious disease outbreak investigations as part of their daily duties, were unable to clearly understand their place or role in the CDC IMS. Despite these difficulties, this version of the CDC IMS remained as the agency's model for the response to public health emergencies until the 2009 H1N1 influenza pandemic.

### CDC IMS: TASK FORCES

"On April 17, 2009, CDC determined that two cases of febrile respiratory illness, occurring in children who resided in adjacent counties in southern California, were caused by infection with a novel swine influenza A (H1N1) virus."<sup>5</sup> In response to this report, the acting CDC director activated the CDC EOC to support the management of the ongoing influenza investigation. The CDC IMS used at the beginning of the response to 2009 H1N1 influenza was based on the TSU model. The traditional public health functions associated with an infectious disease response were located in the TSU and included most subject-matter expertise during the response. However, after the initial wave of 2009 H1N1 influenza subsided in early June, CDC IMS leadership determined that it needed to modify the incident management structure to better organize and manage the needs of the response. Because the scientific/technical teams were the foundation of CDC's public health response to the pandemic, experience suggested that they should not be located within one of the traditional

ICS sections. The CDC IMS leadership determined that the scientific/technical teams should be located in their own section alongside the other ICS functions.

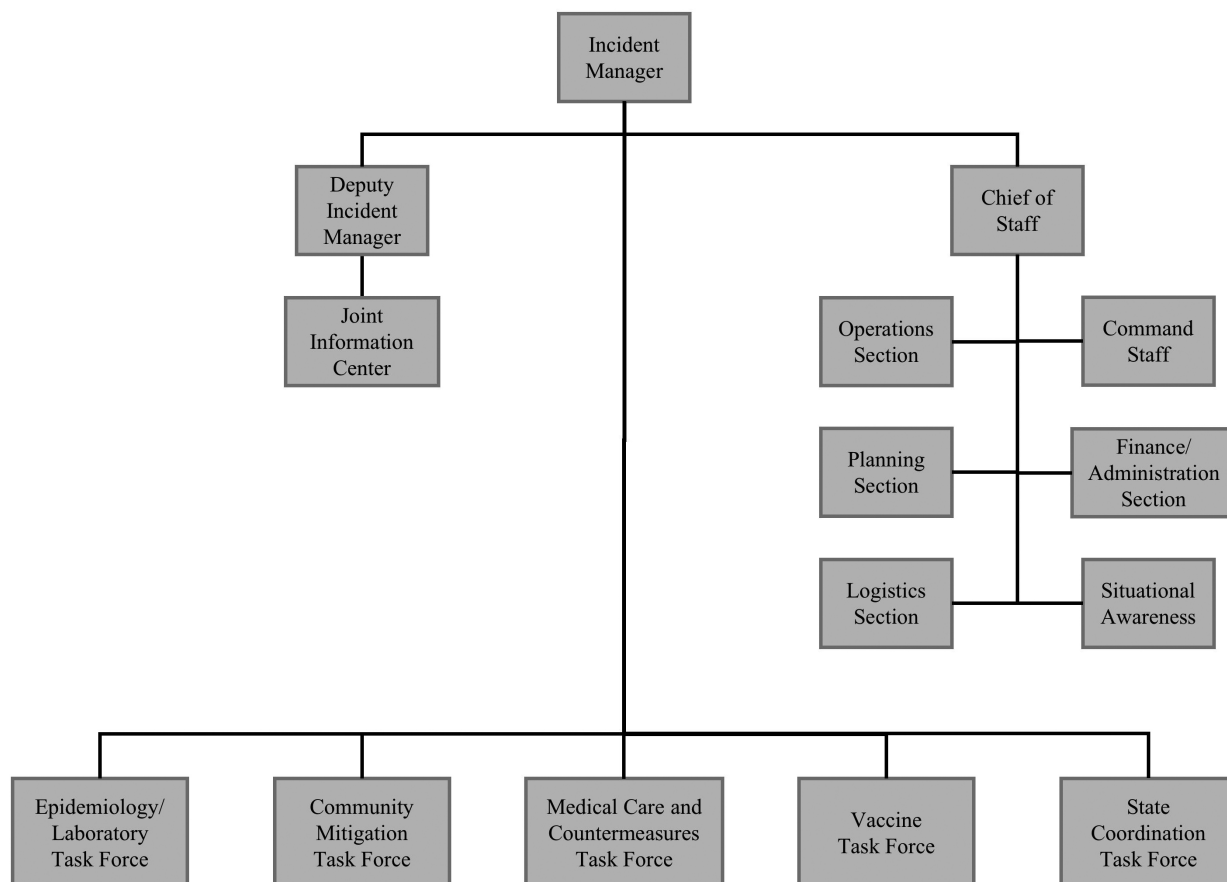
The modified CDC IMS structure was implemented in the fall of 2009, when the structure was modified by removing the TSU from the Planning Section. In its place, CDC created five task forces that addressed specific areas of the influenza response: Epidemiology/Laboratory, Community Mitigation, Vaccine, Medical Care and Countermeasures, and State Coordination, all of which reported directly to the Incident Manager (Figure 3). Although not officially identified as a section, these task forces effectively constituted a science section. These task forces, led by SMEs, were responsible for conducting and coordinating the traditional public health activities associated with the response to an infectious disease outbreak. Because the task forces reported directly to the Incident Manager, response leadership possessed greater oversight and management of the scientific/technical issues. This version (task force) of the CDC IMS remained as the organizational structure for the response from fall 2009 until 2009 H1N1 response operations ended in May 2010.

### CDC IMS: CREATION OF A SCIENCE SECTION

Using the response to 2009 H1N1 influenza as a model, CDC has further adapted its all-hazards IMS structure by creating a Science Section that is responsible for conducting and coordinating the public health activities associated with a response (Figure 4). Also known as the Scientific Response Section, this section reports directly to the Incident Manager or Chief Health Officer, which is staffed by a senior scientist or medical officer who is an SME. The creation of a separate Science Section is consistent with a reference for the creation of an Intelligence/Investigations function, mentioned in the December 2008 version of NIMS. According to NIMS, this function may be necessary "for the collection, analysis, and sharing of information developed during intelligence/investigation efforts."<sup>1</sup> This information includes data (e.g., agent, source, and countermeasures) gathered as part of the public health investigation for a disease outbreak. Furthermore, NIMS indicates that this Intelligence/Investigations function can be located in several places within the incident command/management structure, including being its own section.<sup>1</sup> Therefore, the creation of a new section devoted to scientific/technical issues is in compliance with current NIMS guidance. By creating a separate section devoted to addressing scientific/technical issues, the activities traditionally conducted by public health are more easily integrated into the



**Figure 3. CDC incident management system structure for the response to 2009 H1N1 influenza, modified to include task forces**



CDC = Centers for Disease Control and Prevention

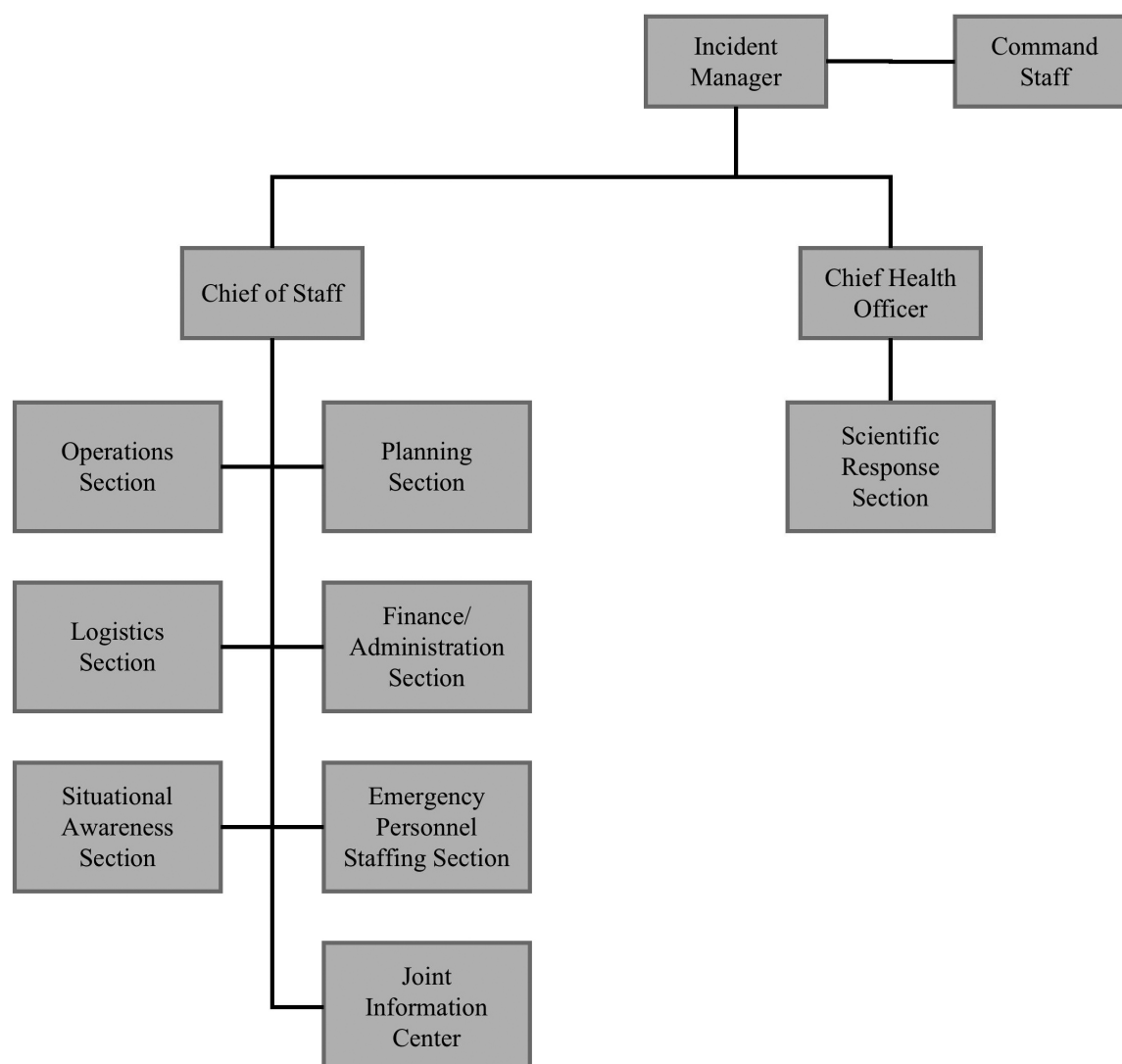
concept of emergency management and align with the traditional sections of ICS, which serve in an equal but primarily supportive role to the scientific investigation.

The creation of a Science Section takes advantage of the ICS principles (flexibility, scalability, and adaptability) and elevates the traditional public health response team concept, which was used by CDC in previous events, to a more prominent role in CDC's IMS. This change allows the Incident Manager to have increased visibility and awareness of the public health activities, which serve as the foundation of CDC's response to an infectious disease outbreak, yet had previously been overshadowed within the CDC IMS structure. Additionally, creating a Science Section may enable public health personnel to more easily adapt to operating within an IMS because they can easily identify their role and function within the structure (i.e., it is consistent and compatible with the activities and functions normally conducted within their program).

Even though the revised CDC IMS structure with a Science Section was developed during the response to an infectious disease outbreak, it was implemented for several recent public health emergencies that were not related to infectious diseases (e.g., Haiti Earthquake and Deepwater Horizon Oil Spill). Currently, this model of the CDC IMS with a Science Section serves as CDC's all-hazard model for the response to public health emergencies.

## CONCLUSIONS

Since the CDC IMS was created, a major challenge has been incorporating the traditional public health functions within a structure that is consistent with NIMS and based on the principles of ICS. Over time, CDC developed an IMS that incorporates a Science Section in conjunction with the traditional ICS sections. Locating the public health functions within their own

**Figure 4. Current all-hazards CDC incident management system structure, incorporating a Science Section**

CDC = Centers for Disease Control and Prevention

section enables agency and/or response leadership to have increased access to and awareness of public health activities, which serve as the foundation of CDC's response to an infectious disease outbreak or other public health emergency. Additionally, it may allow for greater familiarity and ease of use of an IMS by public health responders because they can readily identify the location of their roles/functions within the structure. Although there are differences between CDC and other public health agencies at the federal, state, local, and international level, those agencies that are experiencing difficulties in developing IMSs may want

to consider creating a similar science section within their structure to allow for more effective coordination of the public health response.

Overall, public health needs to better integrate traditional public health practice and functions with the principles of emergency management. Recent changes to NIMS allow public health greater flexibility in organizing and managing response activities while still maintaining compliance with current federal guidance. These changes allow public health to use NIMS/ICS to benefit the response instead of trying to adapt the public health response to NIMS/ICS.

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# An Explanation for the Recent Increase in the Fall Death Rate Among Older Americans: A Subgroup Analysis

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## ABSTRACT

**Objective.** We sought to explain the recent increase in the death rate from falls among Americans aged 65 years and older.

**Methods.** Using the CDC WONDER online database, a longitudinal analysis of subgroups of fall mortality based on the International Classification of Diseases, 10th Revision (ICD-10) was conducted in older adults and in younger people. We used linear regression to examine the statistical significance of trends in mortality rates during 1999–2007.

**Results.** The overall mortality rate from falls increased by 55% among older Americans ( $\geq 65$  years of age) during 1999–2007, from 29 per 100,000 population to 45 per 100,000 population. For those aged  $\geq 65$  years, the largest increase by far (698%) occurred in the subgroup “other falls on the same level,” followed by a moderate increase in falls involving wheelchairs or furniture (48%). The steepest increases at all ages occurred from 1999 to 2000, after ICD-10 took effect. State-level analysis confirmed the findings for the entire United States. From 1999 to 2007, total mortality from falls decreased by 5% in people younger than 45 years of age and increased by 44% for those aged 45–64 years; mortality from “other falls on the same level” increased by 202% and 431%, respectively, in these age groups.

**Conclusions.** Because the reported minor increases in emergency department and hospitalization rates for falls were insignificant, the almost sevenfold increase in death rates from “other falls on the same level” strongly suggests an effect of improved reporting quality.

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Falls among older adults are a serious public health problem. Each year, one in three Americans aged 65 years and older falls.<sup>1,2</sup> The annual direct and indirect cost of fall injuries is expected to reach \$55 billion (in 2007 U.S. dollars) by 2020.<sup>3</sup> A substantial increase in the death rate from unintentional falls has recently been reported among older Americans.<sup>4-9</sup> This increase is perplexing because neither the nonfatal fall rate of 2001–2007 based on Web-based Injury Statistics Query and Reporting System data for patients treated in emergency departments (EDs), nor the fall hospitalization rate of 1997–2005 based on the National Hospital Discharge Survey increased significantly.<sup>9,10</sup> In older people, the rate of ED visits for falls per 100,000 population rose from 4,631 in 2001 to 4,944 in 2007—a 6% increase—compared with a 55% increase in the death rate. This contrasting evidence has raised a critical question: Does the recent increase in fall-related mortality among older Americans reflect an actual increase in fatal falls?

There are several possible explanations for the recent increase in deaths coded with a fall as the underlying cause: (1) an increase in fatal injuries from falls; however, the lack of a corresponding increase in ED cases and in hospitalizations negates this possibility;<sup>9,10</sup> (2) an increase in the case fatality rate, which also appears to be equally unlikely given the general improvement in trauma care and treatment of complications in the United States; and (3) a change in reporting the underlying cause of death,<sup>9</sup> which could have led to the identification of more deaths as having been due to falls.

To provide an explanation of the recent increase in fall mortality, we analyzed changes in mortality during 1999–2007 in the many subgroups of falls. Subgroup analysis provided the opportunity to determine whether the increase was associated with certain types of falls. We studied the fall mortality rates of older Americans, as well as younger age groups, at the national and state level.

**METHODS**

**Data source**

We extracted U.S. mortality data from the Centers for Disease Control and Prevention (CDC) WONDER, the Compressed Mortality File produced by the Office of Analysis and Epidemiology in CDC’s National Center for Health Statistics (NCHS). The Compressed Mortality File is a county-level national mortality and population database spanning the years 1968–2007; data are available on CDC WONDER for the years 1979–2007. Underlying cause of death is classified in accordance

with the International Classification of Diseases (ICD). Deaths for 1979–1998 were classified using the ICD Ninth Revision (ICD-9), while deaths for 1999 and beyond were classified using the ICD 10th Revision (ICD-10).<sup>11</sup>

**Statistical analysis**

Analyses were specific to unintentional falls. Because these types of falls comprise 99.4% of fatal falls at age 65 years or older, we dropped the modifier “unintentional.”

The ICD-10 includes 20 e-codes (sub-causes) for falls, from w00 to w19 (Figure 1). Because the preliminary analysis showed that most of the 20 categories of falls had few deaths and an unstable mortality rate (data not shown), we combined the sub-causes into seven groups based on the mechanism of falls: group 1—slipping/tripping (w00–w01), group 2—involving ice skates/skis/rollerskates/skateboards (w02) or involving another person (w03–w04), group 3—involving wheelchair/furniture (w05–w08), group 4—on/from stairs (w10), group 5—other specified fall (w09, w11–w17), group 6—other falls on the same level (w18), and group 7—unspecified fall (w19).

**Figure 1. 20 subcategories of falls in ICD-10<sup>a</sup>**

| E-code | Description                                                                       |
|--------|-----------------------------------------------------------------------------------|
| w00    | Fall on the same level involving ice and snow                                     |
| w01    | Fall on the same level from slipping, tripping, and stumbling                     |
| w02    | Fall involving ice skates, skis, rollerskates, or skateboards                     |
| w03    | Other fall on the same level due to collision with, or pushing by, another person |
| w04    | Fall while being carried or supported by other people                             |
| w05    | Fall involving wheelchairs                                                        |
| w06    | Fall involving bed                                                                |
| w07    | Fall involving chair                                                              |
| w08    | Fall involving other furniture                                                    |
| w09    | Fall involving playground equipment                                               |
| w10    | Fall on and from stairs and steps                                                 |
| w11    | Fall on and from ladder                                                           |
| w12    | Fall on and from scaffolding                                                      |
| w13    | Fall from, out of, or through building or structure                               |
| w14    | Fall from tree                                                                    |
| w15    | Fall from cliff                                                                   |
| w16    | Diving or jumping into water causing injury other than drowning or submersion     |
| w17    | Other fall from one level to another                                              |
| w18    | Other falls on the same level                                                     |
| w19    | Unspecified fall                                                                  |

<sup>a</sup>Source: World Health Organization. International classification of diseases (ICD) [cited 2011 Mar 1]. Available from: URL: <http://www.who.int/classifications/icd>

ICD-10 = International Classification of Diseases, 10th Revision



We first examined the overall national trend in subgroup-specific mortality rates from 1999 to 2007 to determine the statistical significance of changes. Because groups 1, 2, and 5 did not show a significant increase among older adults, we combined them into a single group. The preliminary results did not vary substantially by gender, race/ethnicity, age, or urbanization, so results for these subgroups are not shown. We did not analyze nonfatal injuries from falls because morbidity data for e-code subgroups were not available.

CDC WONDER suggests that death rates based on counts of  $\leq 20$  are unreliable because of a relative standard error of  $\geq 23\%$ .<sup>11</sup> Because few states have stable mortality rates for specific sub-causes and for all years (1999–2007), for state-level analysis, we combined the sub-causes of falls with specific causes (w00–w17) and unspecified falls (w19) into a single category, as they displayed obviously different time trends in mortality rate compared with other falls on the same level (w18).

To identify sub-causes that most contributed to the recent increase in fall mortality in older adults, we compared those aged  $\geq 65$  years with those aged 0–44 years and 45–64 years. We used linear regression to examine the statistical significance of trends in mortality rates during the study period. We used the percent change in rates to measure the linear trend, which was calculated as regression coefficient  $\times 100 \times 8$  divided by the rate in 1999. We considered an alpha of  $p < 0.05$  to be statistically significant. We used Stata® version 10.0 for data analysis.<sup>12</sup>

## RESULTS

### Sub-cause analysis of fall mortality among older adults

As shown in Table 1, the mortality rate from unintentional falls among older adults increased from 29.4 per 100,000 population in 1999 to 45.3 per 100,000 population in 2007, a 55% increase when calculated by the aforementioned formula. The largest subgroup increase in fall mortality between 1999 and 2007 was observed in other falls on the same level (w18) (698%), followed by a 48% increase in the relatively small group of falls involving wheelchairs/furniture (w05–w08).

### Changes by year, age group, and sub-cause

Fall death rates in younger age groups—those aged 0–44 years and 45–64 years—were much lower but generally followed the same pattern of increase (although less extreme) as that of adults aged  $\geq 65$  years during 1999–2007 (Figure 2). In 2007, the three age groups had 1,252, 3,043, and 18,334 deaths from falls, respectively. The predominant increase was in other falls on the same level (w18), with changes of 202% and 431% in those aged  $\leq 44$  years and 45–64 years, respectively, compared with 698% for those aged  $\geq 65$  years. In each age group, the most dramatic jump in rates for falls on the same level occurred between 1999 and 2000, during which the rate increased at least twofold. After 2000, the rise in mortality from other falls on the same level slowed but was still more striking than increases observed in all other falls.

**Table 1. Mortality rates per 100,000 population from unintentional falls among people  $\geq 65$  years of age: U.S., 1999–2007**

| Sub-cause (ICD-10 code) <sup>a</sup>                                                           | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | Percent change in rates <sup>b</sup> |
|------------------------------------------------------------------------------------------------|------|------|------|------|------|------|------|------|------|--------------------------------------|
| Unintentional falls (w00–w19)                                                                  | 29.4 | 29.6 | 32.7 | 35.2 | 37.0 | 39.5 | 40.8 | 42.1 | 45.3 | 55 <sup>c</sup>                      |
| Slipping/tripping (w00–w01)                                                                    | 1.8  | 1.6  | 1.6  | 1.7  | 1.7  | 1.6  | 1.8  | 1.7  | 1.8  | 3                                    |
| Involving ice skates/skis/rollerskates/skateboards (w02) or involving another person (w02–w04) | 0.1  | 0.2  | 0.3  | 0.2  | 0.1  | 0.0  | 0.1  | 0.1  | 0.1  | –170                                 |
| Involving wheelchairs/furniture (w05–w08)                                                      | 2.1  | 2.1  | 2.2  | 2.5  | 2.6  | 2.6  | 2.9  | 2.9  | 3.0  | 48 <sup>c</sup>                      |
| On/from stairs (w10)                                                                           | 3.0  | 2.7  | 3.0  | 3.3  | 3.2  | 3.1  | 3.2  | 3.3  | 3.5  | 18 <sup>c</sup>                      |
| Other specified fall (w09, w11–w17)                                                            | 1.7  | 1.5  | 1.9  | 1.7  | 1.7  | 1.7  | 1.5  | 1.6  | 1.5  | –10                                  |
| Other falls on the same level (w18)                                                            | 1.6  | 4.0  | 5.3  | 7.9  | 8.5  | 9.7  | 11.2 | 11.7 | 13.0 | 698 <sup>c</sup>                     |
| Unspecified fall (w19)                                                                         | 19.3 | 17.5 | 18.3 | 17.9 | 19.2 | 20.8 | 20.1 | 21.0 | 22.6 | 21 <sup>c</sup>                      |

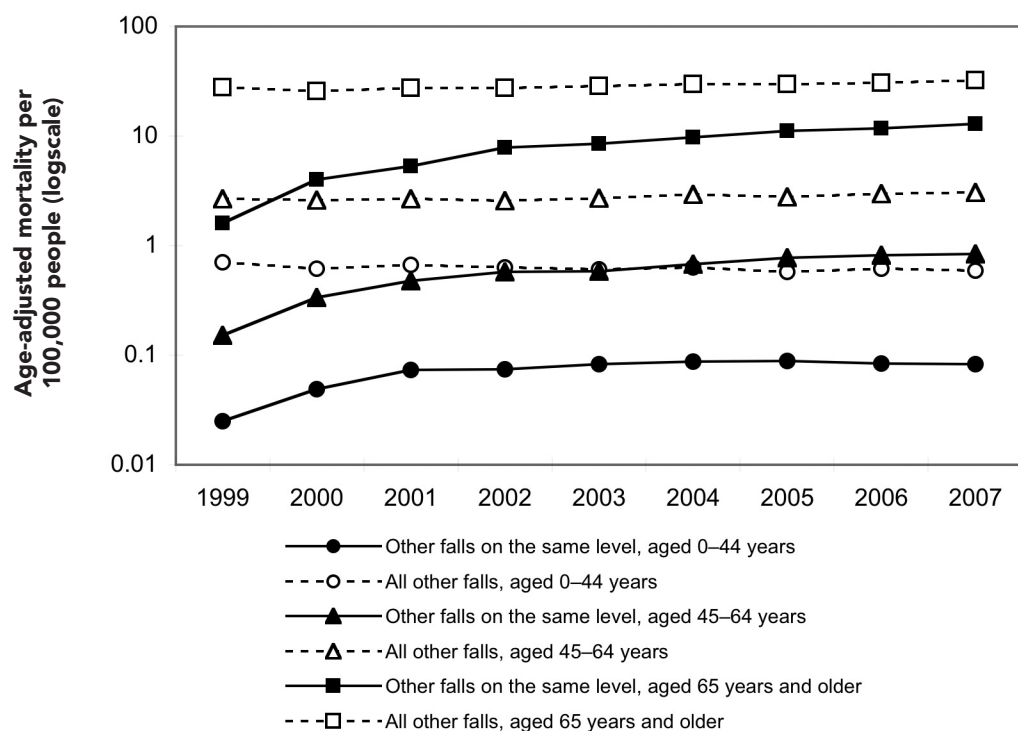
<sup>a</sup>Source: World Health Organization. International classification of diseases (ICD) [cited 2011 Mar 1]. Available from: URL: <http://www.who.int/classifications/icd>

<sup>b</sup>The percent change in rates was calculated as regression coefficient  $\times 100 \times 8$  divided by the rate in 1999.

<sup>c</sup>Statistically significant at  $p < 0.01$

ICD-10 = International Classification of Diseases, 10th Revision

**Figure 2. Mortality rate per 100,000 population from unintentional falls, by age, sub-cause, and year: U.S., 1999–2007**



### State-level analysis

Between 1999 and 2007, 37 states and the District of Columbia experienced a significant increase in death rate from falls in elderly people. Seven of the 37 states (Arizona, California, Illinois, New Mexico, Ohio, Oregon, and Washington) had stable death rates based on having more than 20 deaths from other falls on the same level each year during 1999–2007. All seven states displayed a far greater increase in other falls on the same level than in other categories of falls (Table 2). Due to unstable death rates with a numerator of  $\leq 20$ , corresponding state-level analyses for the elderly in other states and for people younger than 65 years of age were omitted.

### DISCUSSION

The recent rise in the death rate from falls of older Americans during 1999–2007 was primarily due to the previously unreported dramatic nearly sevenfold increase in mortality from the subset other falls on the same level. The same phenomenon occurred in older people in all states having stable fall death rates and, to a lesser extent, among younger age groups.

Falls are more likely to result in delayed death fol-

lowing minor injury among the elderly than in other age groups.<sup>13</sup> Typically, the interval from injury to death is longer for minor or moderate injury than for serious injury. As the interval between injury and death increases, the cause of death is more likely to be attributed to a terminal illness and less likely to be attributed to injury, causing variation in assigning the underlying cause of death.<sup>14</sup>

Other falls on the same level is a category of unspecified fatal fall that is most common in the elderly. A fall on the same level when a person is standing or walking generally does not result in injury that is immediately life-threatening. If death follows a minor injury, such as a rib fracture, it is likely to occur weeks or months later as the result of pneumonia or other complications.<sup>15</sup> People who fill out the underlying cause of death on the death certificate may therefore ignore the fall, and may consider the underlying cause of death to be the terminal illness (e.g., pneumonia or other illness). Older adults have been shown to have significant mortality from minor injuries (Injury Severity Score  $< 9$ ) that have little potential for death in people who are younger than 50 years of age.<sup>13</sup>

The United Nations defines the underlying cause of death as “(a) the disease or injury which initiated

**Table 2. Percent change in fall death rates<sup>a</sup> for people aged ≥65 years in seven states with more than 20 cases of fall-related deaths per year: U.S., 1999–2007**

| State      | All falls                                              | Other falls on the same level                      | Other falls                                                 |
|------------|--------------------------------------------------------|----------------------------------------------------|-------------------------------------------------------------|
|            | (ICD-10 e-code w00–w19) <sup>b</sup><br>Percent change | (ICD-10 e-code w18) <sup>b</sup><br>Percent change | (ICD-10 e-code w00–w17, w19) <sup>b</sup><br>Percent change |
| Arizona    | 56 <sup>c</sup>                                        | 217 <sup>c</sup>                                   | 35 <sup>c</sup>                                             |
| California | 37 <sup>c</sup>                                        | 652 <sup>c</sup>                                   | –7                                                          |
| Illinois   | 41 <sup>c</sup>                                        | 266 <sup>c</sup>                                   | 25 <sup>c</sup>                                             |
| New Mexico | 104 <sup>c</sup>                                       | 178 <sup>c</sup>                                   | –9                                                          |
| Ohio       | 105 <sup>c</sup>                                       | 490 <sup>c</sup>                                   | 69 <sup>c</sup>                                             |
| Oregon     | 125 <sup>c</sup>                                       | 506 <sup>c</sup>                                   | 55                                                          |
| Washington | 61 <sup>c</sup>                                        | 277 <sup>c</sup>                                   | 5                                                           |

<sup>a</sup>The percent change in fall death rate was calculated as regression coefficient × 100 × 8 divided by the rate in 1999.

<sup>b</sup>Source: World Health Organization. International classification of diseases (ICD) [cited 2011 Mar 1]. Available from: URL: <http://www.who.int/classifications/icd>

<sup>c</sup>Statistically significant at  $p < 0.01$

ICD-10 = International Classification of Diseases, 10th Revision

the train of events leading directly to death, or (b) the circumstances of the accident or violence which produced the fatal injury.<sup>16</sup> A review of the literature by Cryer and colleagues<sup>14</sup> describing discrepancies in the reporting of late deaths, especially those due to falls, underscores the need for improved training of nosologists, medical examiners, and coroners. For example, Betz et al.<sup>17</sup> presented physicians and coroners with clinical scenarios of patients who died; however, only 35% correctly indicated that a fall was the underlying cause of death in a person who sustained intracranial bleeding following a fall.

Underscoring the likelihood that the underlying cause of late deaths following falls is often misreported, Goldacre<sup>18</sup> found that only 40% of the death certificates of people who were admitted to a hospital in the Oxford Regional Health Authority with a main diagnosis of injury or poisoning, and then died within a year, specified an injury as the underlying cause of death. Most tellingly, Langlois and colleagues<sup>19</sup> reported that the death rate from falls in the elderly was nearly three times as high in New Zealand as in the U.S., while hospitalization rates for both falls and hip fractures were similar for the two countries. They attributed the difference to coding practices, with a fall-related death in the U.S. being more likely than in New Zealand to be coded with a terminal illness as the underlying cause.

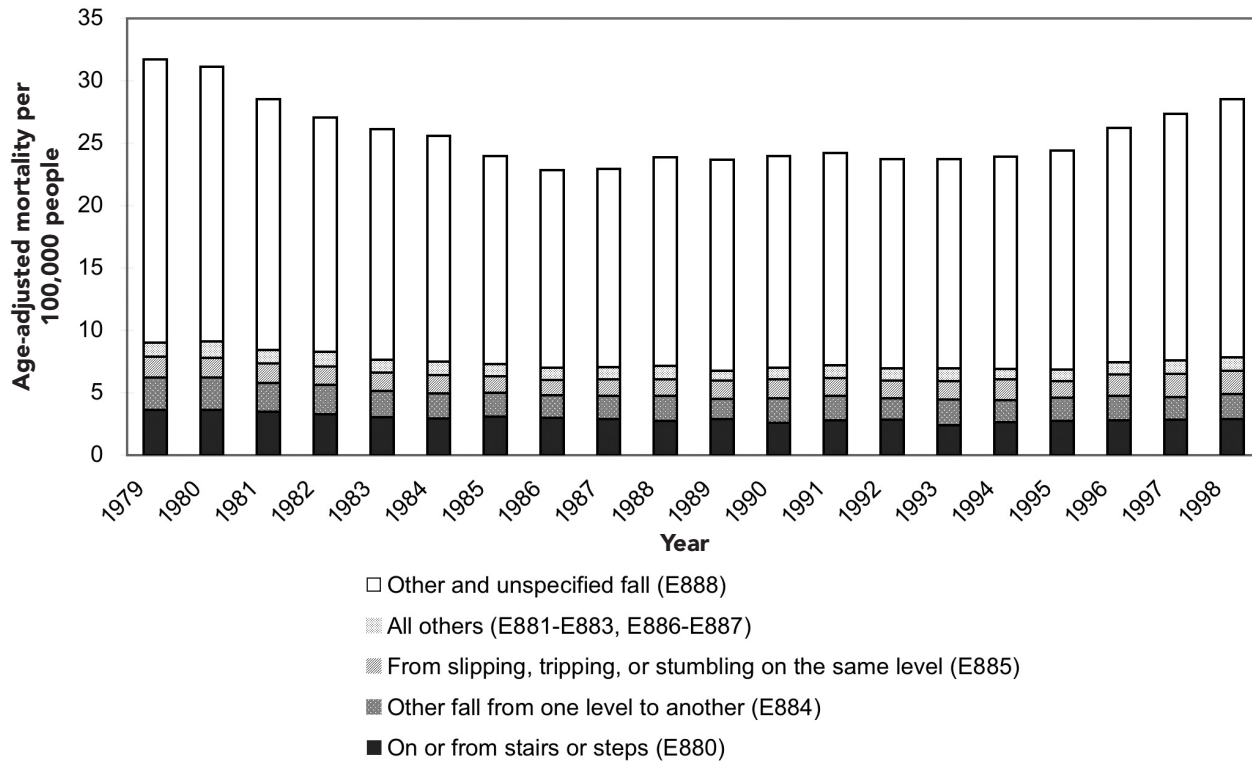
In the U.S., ICD-10 first went into effect in 1999. Although there were moderate increases in reported fall mortality rates from 2000 to 2007, the biggest jump occurred from 1999 to 2000, when rates of deaths coded as other falls on the same level at least

doubled in all age groups (Figure 2). The jump strongly suggests a major change in death certification practices after implementation of ICD-10, followed by a gradual improvement in the quality of certification of belated deaths following falls. A similar but less pronounced increase in fall mortality of older adults occurred between 1993 and 1998 (during the period when falls were recorded using ICD-9 e-codes),<sup>11</sup> probably reflecting the beginning of greater attention to correct coding (Figures 3 and 4). To improve the completeness of e-code reporting and to narrow the variation in completeness of e-code reporting across states,<sup>20</sup> many efforts have been implemented by the U.S. government in recent years, such as the development of strategies to improve external cause-of-injury coding in state-based hospital discharge and ED data systems.<sup>21</sup> Better reporting may also be due to increasing awareness in the past decade of the significance of falls and their contribution to mortality, especially in older age groups.

Because neither the ED visit rate nor the hospitalization rate for falls showed a significant increase during 2001–2007<sup>9</sup> (ED visits) or during 1997–2005 (hospital discharges),<sup>10</sup> the dramatic increase in other falls on the same level was likely the result of improved coding; namely, coding the underlying cause of death as a fall (rather than as pneumonia or some other complication) when delayed death followed a minor injury. In the future, data linkage between different data sources may be a better way to detect deaths related to falls.

In addition to the almost sevenfold increase in deaths from other falls on the same level among those aged ≥65 years, a moderate increase for all ages was

**Figure 3. Mortality per 100,000 population from unintentional falls among adults aged ≥65 years: U.S., 1979–1998<sup>a</sup>**



<sup>a</sup>Source: Centers for Disease Control and Prevention. CDC WONDER: compressed mortality file, underlying cause of death [cited 2011 Mar 1]. Available from: URL: <http://wonder.cdc.gov/mortSQL.html>

identified in the small group of fatal falls involving wheelchairs/furniture and stairs. As with the increase in falls on the same level, this increase probably reflects improvements in specification of the underlying cause

of death, but it also reminds us of the possibility of a real increase in exposure to risk factors for falls.

The authenticity of the recent increase in fall mortality is especially important for the development of fall-prevention strategies for older adults. The indirect evidence of this study offers an explanation for understanding the recent increase in fatal falls in older adults and emphasizes the value of examining the quality of reporting of the underlying cause of death in injuries and of improvement in injury data recording.

### CONCLUSION

The recent dramatic increase in the fall death rate in older Americans is most likely the effect of improved reporting quality. However, more rigorous testing of the hypothesis may be warranted.

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**Figure 4. Nine subcategories of falls in ICD-9<sup>a</sup>**

| E-code | Description                                                                     |
|--------|---------------------------------------------------------------------------------|
| E880   | Fall on or from stairs or steps                                                 |
| E881   | Fall on or from ladders or scaffolding                                          |
| E882   | Fall from or out of building or other structure                                 |
| E883   | Fall into hole or other opening in surface                                      |
| E884   | Other fall from one level to another                                            |
| E885   | Fall on same level from slipping, tripping, or stumbling                        |
| E886   | Fall on same level from collision, pushing, or shoving, by or with other person |
| E887   | Fracture, cause unspecified                                                     |
| E888   | Other and unspecified fall                                                      |

<sup>a</sup>Source: Centers for Disease Control and Prevention. CDC WONDER: compressed mortality file, underlying cause of death [cited 2011 Mar 1]. Available from: URL: <http://wonder.cdc.gov/mortSQL.html>

ICD-9 = International Classification of Diseases, Ninth Revision

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The study was based on publicly available data, and the online agreement for data use restrictions has been signed, ensuring that the data collected by NCHS may be used only for the purposes for which they were obtained; any effort to determine the identity of any reported cases, or to use the information for any purpose other than for health statistical reporting and analysis, is against the law. The study was exempted from review by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board. The findings and conclusions in this article are those of the authors and do not necessarily reflect the views of CDC.

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# A Tale of Two Gonorrhea Epidemics: Results from the STD Surveillance Network

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## ABSTRACT

**Objective.** An increasing proportion of gonorrhea in the United States is diagnosed in the private sector, posing a challenge to existing national surveillance systems. We described gonorrhea epidemiology outside sexually transmitted disease (STD) clinic settings.

**Methods.** Through the STD Surveillance Network (SSuN), health departments in the San Francisco, Seattle, Denver, Minneapolis, and Richmond, Virginia, metropolitan areas interviewed systematic samples of men and women reported with gonorrhea by non-STD clinic providers from 2006 through 2008.

**Results.** Of 2,138 interviews, 10.0% were from San Francisco, 26.4% were from Seattle, 25.2% were from Denver, 22.9% were from Minneapolis, and 15.5% were from Richmond. A total of 1,165 women were interviewed; 70.1% (815/1,163) were  $\leq 24$  years of age, 51.3% (598/1,165) were non-Hispanic black, and 19.0% (213/1,121) reported recent incarceration of self or sex partner. Among 610 men who have sex with only women, 50.9% were  $\leq 24$  years of age, 65.1% were non-Hispanic black, 14.1% reported incarceration of self or sex partner, and 16.7% reported anonymous sex. Among 363 men who have sex with men (MSM), 20.9% were  $\leq 24$  years of age, 61.6% were non-Hispanic white, 39.8% reported anonymous sex, 35.7% reported using the Internet to meet sex partners, and 12.1% reported methamphetamine use.

**Conclusions.** These data identified two concurrent gonorrhea epidemics in minority populations: a young, black, heterosexual epidemic with frequently reported recent incarceration, and an older, mostly white MSM epidemic with more frequently reported anonymous sex, Internet use to meet sex partners, and methamphetamine use.

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Untreated *Neisseria gonorrhoeae* (*N. gonorrhoeae*) infection may lead to pelvic inflammatory disease, ectopic pregnancy, infertility, and chronic pelvic pain.<sup>1</sup> In addition, infection with *N. gonorrhoeae* increases the risk of human immunodeficiency virus (HIV) transmission and acquisition.<sup>2</sup> Gonorrhea, a reportable disease in all 50 U.S. states, is the second most common notifiable disease.<sup>3</sup> In 2008, approximately 350,000 gonorrhea cases were reported to the Centers for Disease Control and Prevention (CDC), with a national rate of 111.6 cases per 100,000 population.<sup>4</sup>

Despite the large number of individuals affected and the severity of the sequelae of gonorrhea, national surveillance data contain only basic information on the gender, age, race/ethnicity, and county of residence of individuals with gonorrhea. In 2008, 77% of all reported cases of gonorrhea came from providers outside the sexually transmitted disease (STD) clinic and 54% were among women. National case-report data show that gonorrhea rates vary widely by race/ethnicity and residence. In 2009, rates were 20 times higher among non-Hispanic black people than among non-Hispanic white people, with estimates suggesting three cases of gonorrhea for every 100 black 15- to 19-year-old women. In 2008, 22.3% of 3,141 counties in the U.S. had gonorrhea rates that were higher than 100 cases per 100,000 population, with the majority of these cases concentrated in the South.<sup>4</sup> In addition to limited data on infected individuals, current gonorrhea surveillance is limited by incomplete reporting. Many infections are asymptomatic and, thus, go undiagnosed; diagnosed infections may be unreported; and information on reported cases is often incomplete.<sup>5</sup> In 2008, for example, race or ethnicity was missing on 20.3% of case reports.<sup>4</sup>

In addition to case-report data, another source of national data on patients with gonorrhea has been through the Gonococcal Isolate Surveillance Project (GISP), a sentinel surveillance project that collects gonococcal specimens and demographic, behavioral, and clinical data on men diagnosed with gonorrhea in approximately 30 STD clinics. GISP has been an important source for understanding trends in gonococcal susceptibility and characteristics of men who seek care for gonorrhea at publicly funded STD clinics. However, GISP does not provide information on women with gonorrhea, nor on the approximately 70% of men who receive care for gonorrhea from providers other than STD clinics.<sup>4</sup>

To better support the prevention and control of gonorrhea, additional as well as more complete information is needed on a broad cross-section of affected individuals on a routine basis. In response to such

surveillance needs, CDC established in 2005 the STD Surveillance Network (SSuN),<sup>6</sup> a dynamic STD surveillance network comprising a number of local health departments following common protocols to collect, analyze, and interpret disease data. The purpose of the SSuN was to fill critical gaps in national surveillance and improve the capacity of state and local STD programs to act rapidly.

In this descriptive analysis, enhanced gonorrhea surveillance data from SSuN Cycle 1 (2005–2008) were used to describe the epidemiology of gonorrhea among men and women diagnosed outside the STD clinic setting in five geographically diverse metropolitan areas in the U.S. We discuss implications of the findings for gonorrhea-control programs and future gonorrhea surveillance activities.

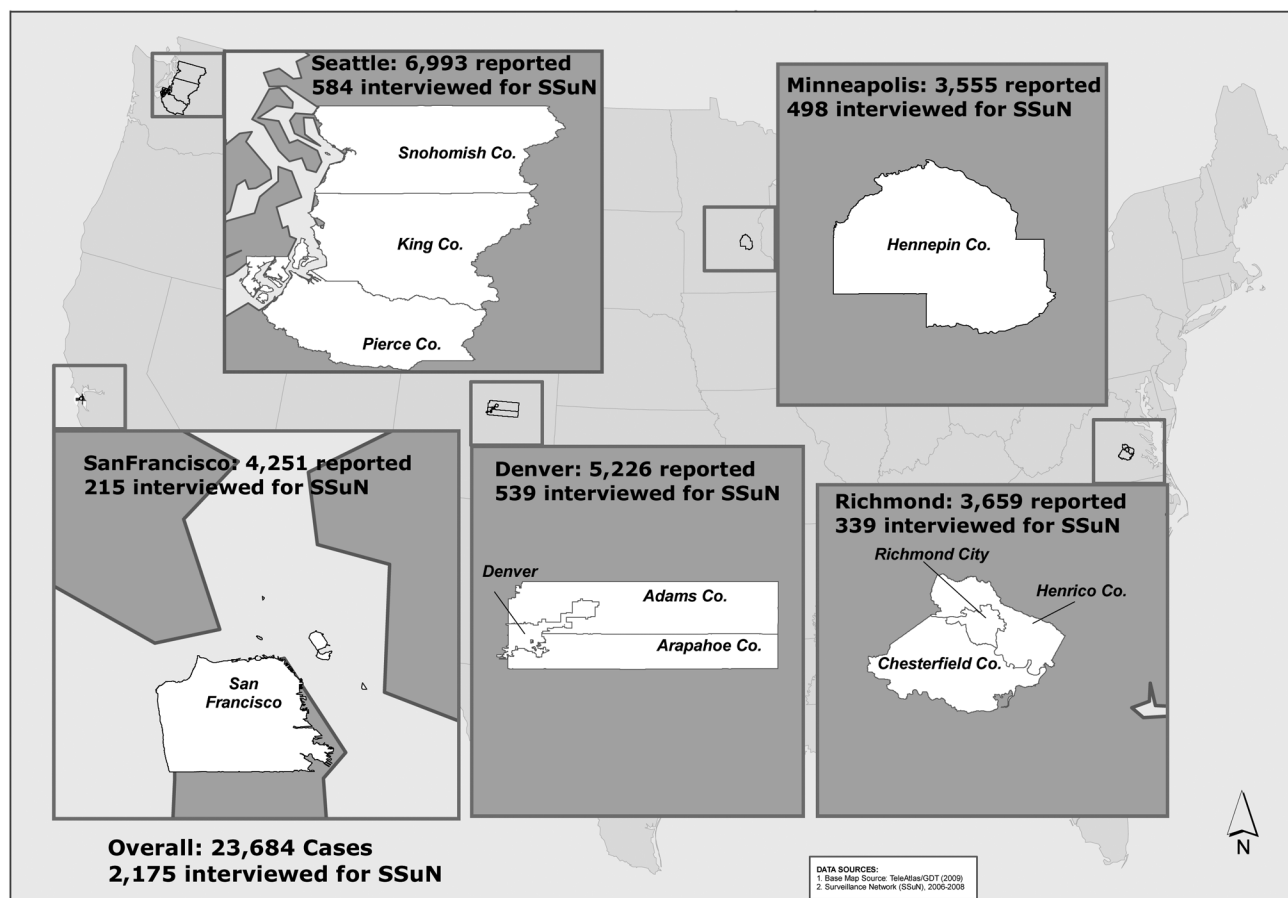
## METHODS

Participating SSuN Cycle 1 sites identified one or more counties in which to conduct enhanced gonorrhea surveillance activities. For this analysis, the term “metropolitan area” was used to informally describe the clusters of counties in which surveillance activities were conducted around the cities of San Francisco, California; Seattle, Washington; Denver, Colorado; Minneapolis, Minnesota; and Richmond, Virginia (Figure). The data-collection time period varied by metropolitan area: San Francisco (August 1, 2006, to August 5, 2008), Seattle (April 1, 2006, to December 31, 2008), Denver (March 1, 2006, to December 31, 2008), Minneapolis (July 1, 2006, to August 31, 2008), and Richmond (January 1, 2007, to December 31, 2008).

Each site collected a common set of demographic, clinical, and behavioral data on a sample of patients reported with gonorrhea. In Denver, Minneapolis, Richmond, and Seattle, the first patients reported by providers or laboratories to the health department in participating counties each calendar month were selected for interview until 10 male and 10 female patients were interviewed. In San Francisco, a variable proportion of patients was sampled from all cases reported by providers or laboratories on a weekly basis, with adjustments made for nonresponse, for a target interviewed sample size of 100 men and 100 women annually. All sites excluded patients reported by STD clinics from SSuN county sampling, as the SSuN had a separate system of data collection for STD clinic patients.

To integrate with existing disease-control activities, interviews of SSuN patients were conducted by health department staff using locally developed data-collection instruments. However, data-collection instruments from

**Figure. Number of gonorrhea cases reported in five metropolitan areas and number of gonorrhea cases interviewed through the SSuN, 2006–2008**



SSuN = Sexually Transmitted Disease Surveillance Network

all sites used a common set of demographic, clinical, and behavioral variables. Prior to initiation, this activity was determined to be a non-research surveillance activity by the CDC National Center for HIV, Viral Hepatitis, STD, and Tuberculosis Prevention.

We examined SSuN interview data from March 1, 2006, through December 31, 2008. For this evaluation, we defined men who have sex with men (MSM) as men who either reported sex with a man in the three months before being tested for gonorrhea (asked in all areas) or did not report the sex of their partner and reported that they were gay/homosexual or bisexual (asked only in Denver and San Francisco). We defined men who have sex only with women (MSW) as men who reported sex only with women in the three months before being tested for gonorrhea or did not report being gay/homosexual or bisexual. Race and ethnicity were coded separately in data-collection instruments at

all sites but were combined for this analysis, such that any patient who reported being of Hispanic ethnicity was classified as Hispanic irrespective of reported race.

All analyses were stratified by gender and sexual behavior or sexual orientation. Because only nine MSW in San Francisco and 17 MSM in Richmond were interviewed, data on these patients are not presented in any analysis stratified by sexual behavior or orientation to avoid over-interpretation of data from samples that were too small to be reliable. We assessed representativeness using Chi-square statistics comparing the proportions of SSuN-interviewed patients  $\leq 24$  years of age and of non-Hispanic black race/ethnicity with those of non-STD clinic non-interviewed patients. Chi-square statistics were also used to assess the significance of differences in characteristics among women, MSW, and MSM. We conducted all analyses using SAS<sup>®</sup> version 9.1.<sup>7</sup>

## RESULTS

The five metropolitan areas received case reports of 23,684 individuals with gonorrhea during the surveillance period (range by site: 3,555 in Minneapolis to 6,993 in Seattle) (Figure). Of these gonorrhea case reports, 6,623 were reported by the primary STD clinics and excluded. Of the remaining 17,061 cases, 10,006 were selected for SSuN interviews, of whom 2,175 were successfully interviewed. This figure corresponded to an interview success rate of 21.7% overall, with slight variation by site: Seattle = 19.0%, Richmond = 19.2%, Denver = 20.0%, San Francisco = 27.1%, and Minneapolis = 29.6% (data not shown).

To better understand how a low response rate might be affecting the SSuN sample, we compared SSuN-interviewed patients with patients who were selected for interview but could not be interviewed for any reason (e.g., four interviewed patients were removed from analysis: two due to lack of information on age and two due to gender reported as transgender). Interviewed and non-interviewed men were of similar age (39.9% of interviewed men and 38.9% of non-interviewed men were ≤24 years of age); however, interviewed men were significantly less likely to be non-Hispanic black than were non-interviewed men (49.4% vs. 56.1%, respectively). Compared with non-interviewed women, interviewed women were significantly more likely to be ≤24 years of age (70.1% vs. 66.8%, respectively) and less likely to be non-Hispanic black (54.7% vs. 58.2%, respectively) (Table 1).

We excluded 37 males (3.8%) from the analysis who had missing gender of sex partners and unknown sexual orientation. Of 2,138 interviews, 10.0% were from San Francisco, 26.4% were from Seattle, 25.2% were from Denver, 22.9% were from Minneapolis, and 15.5% were from Richmond. Consistent with the SSuN sampling methodology, which was stratified by gender, 1,165 of 2,138 SSuN interviews (54.5%) were women, 610 were MSW (28.5%), and 363 were MSM (17.0%). Of 973 men reporting either gender of sex partners, sexual orientation, or both, the proportion of men with gonorrhea who were MSM varied widely by site: San Francisco (92.0%), Seattle (43.8%), Denver (29.6%), Minneapolis (25.6%), and Richmond (12.5%) (data not shown).

### Women

A total of 1,165 women with gonorrhea were interviewed through the SSuN (range by site: 100 in San Francisco to 307 in Seattle); 70.1% were ≤24 years of age (range by site: 55.0% in San Francisco to 79.9% in Richmond). Overall, the majority of interviewed women were non-Hispanic black (51.3%), although this percentage varied widely from 30.6% in Seattle to 85.2% in Richmond. Overall, 21.4% of interviewed women were non-Hispanic white; this proportion ranged from 7.7% in Richmond to 31.9% in Seattle. Denver was the only area where a sizable proportion of women reported Hispanic ethnicity (34.7%) (Table 2).

Overall, the most common practice setting reporting women with gonorrhea was primary care (35.5%).

**Table 1. Comparison of age and race/ethnicity between interviewed patients and patients who were selected but not interviewed<sup>a</sup> through the STD Surveillance Network,<sup>b</sup> 2006–2008**

| Variable                       | Age ≤24 years<br>Percent (N)    | Non-Hispanic black<br>Percent (N) |
|--------------------------------|---------------------------------|-----------------------------------|
| Overall (n=9,994) <sup>c</sup> |                                 |                                   |
| Interviewed (n=2,171)          | 56.1 <sup>d</sup> (1,217/2,171) | 52.2 <sup>d</sup> (1,071/2,050)   |
| Non-interviewed (n=7,823)      | 53.5 (4,186/7,823)              | 57.3 (3,179/5,552)                |
| Women                          |                                 |                                   |
| Interviewed (n=1,163)          | 70.1 <sup>d</sup> (815/1,163)   | 54.7 <sup>d</sup> (598/1,093)     |
| Non-interviewed (n=4,088)      | 66.8 (2,732/4,088)              | 58.2 (1,703/2,924)                |
| Men                            |                                 |                                   |
| Interviewed (n=1,008)          | 39.9 (402/1,008)                | 49.4 <sup>d</sup> (473/957)       |
| Non-interviewed (n=3,735)      | 38.9 (1,454/3,735)              | 56.1 (1,476/2,633)                |

<sup>a</sup>Due to missing race/ethnicity, 121 patients were excluded.

<sup>b</sup>The STD Surveillance Network comprised health departments in the San Francisco, Seattle, Denver, Minneapolis, and Richmond, Virginia, metropolitan areas.

<sup>c</sup>Two interviewed patients were excluded due to missing age, and two interviewed patients were excluded due to gender reported as transgender.

<sup>d</sup>Statistically significant at  $p < 0.05$  between interviewed and non-interviewed patients

STD = sexually transmitted disease

**Table 2. Reported characteristics of women with gonorrhea interviewed in the STD Surveillance Network, 2006–2008**

| Characteristic                                    | San Francisco<br>(n=100)<br>Percent (N) | Seattle<br>(n=307)<br>Percent (N) | Denver<br>(n=291)<br>Percent (N) | Minneapolis<br>(n=271)<br>Percent (N) | Richmond, VA<br>(n=196)<br>Percent (N) | Total<br>(n=1,165)<br>Percent (N) |
|---------------------------------------------------|-----------------------------------------|-----------------------------------|----------------------------------|---------------------------------------|----------------------------------------|-----------------------------------|
| Age (in years)                                    |                                         |                                   |                                  |                                       |                                        |                                   |
| ≤24                                               | 55.0 (55/100)                           | 73.3 (225/307)                    | 65.6 (191/291)                   | 69.7 (189/271)                        | 79.9 (155/194)                         | 70.1 (815/1,163)                  |
| Race/ethnicity                                    |                                         |                                   |                                  |                                       |                                        |                                   |
| American Indian/Alaska Native                     | 0.0 (0/100)                             | 2.3 (7/307)                       | 0.7 (2/291)                      | 2.6 (7/271)                           | 0.0 (0/196)                            | 1.4 (16/1,165)                    |
| Non-Hispanic Asian                                | 8.0 (8/100)                             | 1.0 (3/307)                       | 0.7 (2/291)                      | 1.9 (5/271)                           | 0.5 (1/196)                            | 1.6 (19/1,165)                    |
| Non-Hispanic black                                | 60.0 (60/100)                           | 30.6 (94/307)                     | 37.5 (109/291)                   | 62.0 (168/271)                        | 85.2 (167/196)                         | 51.3 (598/1,165)                  |
| Hispanic                                          | 10.0 (10/100)                           | 7.2 (22/307)                      | 34.7 (101/291)                   | 3.7 (10/271)                          | 1.5 (3/196)                            | 12.5 (146/1,165)                  |
| Non-Hispanic white                                | 17.0 (17/100)                           | 31.9 (98/307)                     | 21.0 (61/291)                    | 21.4 (58/271)                         | 7.7 (15/196)                           | 21.4 (249/1,165)                  |
| Other/multiracial                                 | 4.0 (4/100)                             | 4.6 (14/307)                      | 5.5 (16/291)                     | 8.1 (22/271)                          | 4.6 (9/196)                            | 5.6 (65/1,165)                    |
| No answer                                         | 1.0 (1/100)                             | 22.5 (69/307)                     | 0.0 (0/291)                      | 0.4 (1/271)                           | 0.5 (1/196)                            | 6.2 (72/1,165)                    |
| Practice setting                                  |                                         |                                   |                                  |                                       |                                        |                                   |
| ER/urgent care                                    | 8.0 (8/100)                             | 16.3 (50/307)                     | 23.7 (69/291)                    | 16.6 (45/271)                         | 66.8 (131/196)                         | 26.0 (303/1,165)                  |
| Family planning/gynecology                        | 9.0 (9/100)                             | 15.6 (48/307)                     | 11.7 (34/291)                    | 11.8 (32/271)                         | 6.6 (13/196)                           | 11.7 (136/1,165)                  |
| Hospital (non-ER)                                 | 34.0 (34/100)                           | 8.1 (25/307)                      | 17.5 (51/291)                    | NA                                    | 1.0 (2/196)                            | 12.5 (112/894)                    |
| Jail/prison                                       | 12.0 (12/100)                           | 4.2 (13/307)                      | 2.4 (7/291)                      | 0.4 (1/271)                           | NA                                     | 3.4 (33/969)                      |
| Primary care                                      | 29.0 (29/100)                           | 30.0 (93/307)                     | 36.8 (107/291)                   | 53.1 (144/271)                        | 20.9 (41/196)                          | 35.5 (414/1,165)                  |
| Other                                             | 3.0 (3/100)                             | 14.7 (45/307)                     | 7.9 (23/291)                     | 12.6 (34/271)                         | 4.1 (8/196)                            | 9.7 (113/1,165)                   |
| No answer                                         | 5.0 (5/100)                             | 10.8 (33/307)                     | 0.0 (0/291)                      | 5.5 (15/271)                          | 0.5 (1/196)                            | 4.6 (54/1,165)                    |
| Behavioral (past three months)                    |                                         |                                   |                                  |                                       |                                        |                                   |
| Median number of sex partners (N)                 | 1                                       | 1                                 | 1                                | 1                                     | 1                                      | 1                                 |
| Internet to meet sex partners                     | 2.1 (2/97)                              | 3.4 (9/269)                       | 1.4 (4/288)                      | 1.5 (4/271)                           | 1.1 (2/190)                            | 1.9 (21/1,115)                    |
| Anonymous sex                                     | 19.6 (19/97)                            | NA                                | 6.6 (19/288)                     | 10.7 (29/271)                         | 12.2 (23/188)                          | 10.7 (90/844)                     |
| Methamphetamine use                               | 4.0 (4/99)                              | 5.1 (13/257)                      | 1.4 (4/288)                      | 0.4 (1/271)                           | 0.0 (0/54)                             | 2.3 (22/969)                      |
| Exchange of money or drugs for sex                | 9.2 (9/98)                              | 6.4 (18/282)                      | 1.4 (4/288)                      | 0.7 (2/271)                           | 1.1 (2/190)                            | 3.1 (35/1,129)                    |
| Incarceration of self or sex partner              | 28.9 (28/97)                            | 26.2 (72/275)                     | 13.9 (40/288)                    | 14.1 (38/270)                         | 18.3 (35/191)                          | 19.0 (213/1,121)                  |
| Partner                                           |                                         |                                   |                                  |                                       |                                        |                                   |
| Seeking care because sex partner has STD          | 0.0 (0/99)                              | 8.8 (27/307)                      | 15.6 (44/286)                    | 22.5 (60/267)                         | 24.9 (47/189)                          | 15.5 (178/1,148)                  |
| Sex with partner since being tested for gonorrhea | 28.8 (28/97)                            | NA                                | 24.8 (71/286)                    | 32.2 (86/267)                         | 27.8 (52/187)                          | 28.3 (237/837)                    |
| Sure partner received treatment                   | 48.1 (38/79)                            | 57.1 (109/191)                    | 48.8 (138/283)                   | 47.6 (127/267)                        | 50.8 (91/179)                          | 50.4 (503/999)                    |
| Clinical history                                  |                                         |                                   |                                  |                                       |                                        |                                   |
| Symptomatic                                       | 29.3 (29/99)                            | 80.9 (203/251)                    | 65.1 (188/289)                   | 53.1 (144/271)                        | 41.7 (80/192)                          | 58.4 (644/1,102)                  |
| If symptomatic, median days to seeking care (N)   | NA                                      | 7                                 | 7                                | 4                                     | 7                                      | 7                                 |
| History of gonorrhea in last 12 months            | 3.5 (3/87)                              | 10.6 (28/265)                     | 6.3 (13/206)                     | 8.1 (17/210)                          | 2.1 (4/191)                            | 6.8 (65/959)                      |
| Ever tested for HIV                               | 100.0 (89/89)                           | 77.9 (211/271)                    | 78.1 (221/283)                   | 84.6 (225/266)                        | 74.7 (142/190)                         | 80.8 (888/1,099)                  |
| HIV-positive at time of visit                     | 0.0 (0/82)                              | 0.0 (0/267)                       | 0.5 (1/204)                      | 1.0 (2/211)                           | 0.8 (1/133)                            | 0.5 (4/897)                       |

STD = sexually transmitted disease

ER = emergency room

NA = not available

HIV = human immunodeficiency virus



However, a significant proportion of women in Richmond were diagnosed in emergency room (ER)/urgent care settings (66.8%); in San Francisco, 34.0% of women were diagnosed in non-ER hospital settings and 12.0% were diagnosed in jails/prisons. Overall, 80.8% of women reported ever being tested for HIV (range by site: 74.7% in Richmond to 100.0% in San Francisco) and 0.5% reported being HIV-positive. A total of 6.8% of women had a history of gonorrhea in the past 12 months (Table 2).

Symptoms of gonorrhea were reported by 58.4% of women, though this percentage varied widely by site (29.3% in San Francisco to 80.9% in Seattle). Women reporting symptoms said they waited a median of seven days (individual range: 0–365) before seeking care. A total of 15.5% of women reported seeking care because a sex partner had an STD, though this figure also varied widely by site (range: 0.0% in San Francisco to 24.9% in Richmond). Among women, 28.3% reported having sex with their partner since being diagnosed with gonorrhea. Only 50.4% of women reported being sure that their partner had been treated, with minimal variation by site for both issues (Table 2).

Incarceration of self or sex partner in the past three months was reported by 19.0% of women with gonorrhea interviewed through the SSuN (range by site: 13.9% in Minneapolis to 28.9% in San Francisco). All other measured risk factors were relatively uncommon among women with gonorrhea. Although uncommon in all sites, West Coast sites (San Francisco and Seattle) reported slightly higher Internet use to meet sex partners, anonymous sex, exchange of money or drugs for sex, and methamphetamine use (Table 2).

### MSW

A total of 601 MSW reported with gonorrhea were interviewed through the SSuN (range by site: 119 in Richmond to 163 in Minneapolis; total excludes nine MSW from San Francisco). Of these 601 MSW, 50.9% were  $\leq 24$  years of age. The majority of MSW with gonorrhea in all SSuN sites were non-Hispanic black (65.1%), though this figure ranged from 41.4% in Seattle to 85.7% in Richmond. Seattle was the only site with a sizable proportion (25.5%) of non-Hispanic white MSW. In Denver, 20.7% of MSW were Hispanic (Table 3).

MSW with gonorrhea presented most frequently to primary care providers (40.8%; range by site: 29.7% in Seattle to 49.6% in Richmond). However, all SSuN sites also reported a large proportion of MSW from ERs/urgent care centers (30.8%; range by site: 19.3% in Seattle to 48.7% in Richmond). By self-report, 75.1% of all MSW had ever been tested for HIV, but only 0.9%

were HIV-positive at the time of current visit. Though 9.7% of MSW reported a history of gonorrhea in the last 12 months, this figure ranged from 4.4% in Denver to 18.9% in Seattle. At the time of diagnosis, 79.1% of all MSW reported symptoms of gonorrhea (range by site: 52.1% in Richmond to 95.2% in Seattle); the median number of days before seeking care for symptomatic men was three (individual range: 0–120) (Table 3).

Overall, 19.4% of MSW sought care because a sex partner had an STD. Among MSW, 23.0% reported having had sex since being tested for gonorrhea. Only 47.1% of MSW were sure that their partner had received treatment for gonorrhea (Table 3).

Risk behaviors reported by MSW varied across SSuN sites. Overall, the most common risk behaviors reported were anonymous sex (16.7%) and incarceration of self or sex partner (14.1%). The median reported number of sex partners for MSW was two in the past three months. In general, methamphetamine use, exchange of sex for drugs or money, and use of the Internet to meet sex partners were uncommonly reported by MSW (Table 3).

### MSM

A total of 346 MSM reported with gonorrhea were interviewed through the SSuN (range by site: 56 in Minneapolis to 113 in Seattle; total excludes 17 MSM from Richmond); 20.9% were  $\leq 24$  years of age. The majority of MSM reported with gonorrhea in all SSuN sites were non-Hispanic white (61.6%; range by site: 44.3% in Seattle to 74.0% in Denver). Only Seattle and Minneapolis reported any significant proportions of non-Hispanic black MSM (23.0% and 19.6%, respectively) (Table 4).

Although overall the most common practice setting reporting MSM with gonorrhea was primary care (43.4%; range by site: 34.6% in San Francisco to 73.2% in Minneapolis), 53.9% of MSM with gonorrhea in San Francisco were reported by other providers, principally a gay men's health center. Overall, 92.6% of MSM had ever been tested for HIV. Self-reported HIV positivity at the time of visit was 29.1% overall, ranging from 7.8% in Seattle to 47.3% in San Francisco. A history of gonorrhea in the past 12 months was reported by 12.8% of MSM with gonorrhea.

Overall, 67.9% of MSM reported symptoms of gonorrhea; however, in San Francisco, only 18.8% of MSM were symptomatic compared with Minneapolis, Seattle, and Denver, where 83.9%, 86.7%, and 94.5% of MSM, respectively, were symptomatic. For symptomatic MSM, the median number of days before seeking care was three (individual range: 0–210) (Table 4). Rectal infection was reported among 37.5% of MSM in San

**Table 3. Reported characteristics of MSW with gonorrhea interviewed in the STD Surveillance Network, 2006–2008<sup>a</sup>**

| Characteristic                                    | Seattle<br>(n = 145)<br>Percent (N) | Denver<br>(n = 291)<br>Percent (N) | Minneapolis<br>(n = 163)<br>Percent (N) | Richmond, VA<br>(n = 119)<br>Percent (N) | Total<br>(n = 601)<br>Percent (N) |
|---------------------------------------------------|-------------------------------------|------------------------------------|-----------------------------------------|------------------------------------------|-----------------------------------|
| Age (in years)                                    |                                     |                                    |                                         |                                          |                                   |
| ≤24                                               | 51.0 (75/145)                       | 47.1 (82/174)                      | 57.7 (94/163)                           | 47.1 (56/119)                            | 50.9 (306/601)                    |
| Race/ethnicity                                    |                                     |                                    |                                         |                                          |                                   |
| American Indian/Alaska Native                     | 0.0 (0/145)                         | 0.6 (1/174)                        | 1.2 (2/163)                             | 0.0 (0/119)                              | 0.5 (3/601)                       |
| Non-Hispanic Asian                                | 1.4 (2/145)                         | 0.0 (0/174)                        | 0.0 (0/163)                             | 0.0 (0/119)                              | 0.3 (0/601)                       |
| Non-Hispanic black                                | 41.4 (60/145)                       | 58.6 (102/174)                     | 77.9 (127/163)                          | 85.7 (102/119)                           | 65.1 (391/601)                    |
| Hispanic                                          | 6.9 (10/145)                        | 20.7 (36/174)                      | 6.8 (11/163)                            | 1.7 (2/119)                              | 9.8 (59/601)                      |
| Non-Hispanic white                                | 25.5 (37/145)                       | 13.8 (24/174)                      | 9.2 (15/163)                            | 10.1 (12/119)                            | 14.6 (88/601)                     |
| Other/multiracial                                 | 6.2 (9/145)                         | 6.3 (11/174)                       | 4.3 (7/163)                             | 2.5 (3/119)                              | 5.0 (30/601)                      |
| No answer                                         | 18.6 (27/145)                       | 0.0 (0/174)                        | 0.6 (1/163)                             | 0.0 (0/119)                              | 4.7 (28/601)                      |
| Practice setting                                  |                                     |                                    |                                         |                                          |                                   |
| ER/urgent care                                    | 19.3 (28/145)                       | 27.0 (47/174)                      | 31.9 (52/163)                           | 48.7 (58/119)                            | 30.8 (185/601)                    |
| Family planning/gynecology                        | 10.3 (15/145)                       | 8.1 (14/174)                       | 3.1 (5/163)                             | 0.0 (0/119)                              | 5.7 (34/601)                      |
| Hospital (non-ER)                                 | 10.3 (15/145)                       | 16.1 (28/174)                      | NA                                      | 0.8 (1/119)                              | 10.0 (44/438)                     |
| Jail/prison                                       | 4.1 (6/145)                         | 6.3 (11/174)                       | 1.8 (3/163)                             | NA                                       | 4.1 (20/482)                      |
| Primary care                                      | 29.7 (43/145)                       | 37.9 (66/174)                      | 47.2 (77/163)                           | 49.6 (59/119)                            | 40.8 (245/601)                    |
| Other                                             | 19.3 (28/145)                       | 4.6 (8/174)                        | 13.5 (22/163)                           | 0.8 (1/119)                              | 9.8 (59/601)                      |
| No answer                                         | 6.9 (10/145)                        | 0.0 (0/174)                        | 2.5 (4/163)                             | 0.0 (0/119)                              | 2.3 (14/601)                      |
| Behavioral (past three months)                    |                                     |                                    |                                         |                                          |                                   |
| Median number of sex partners (N)                 | 1                                   | 2                                  | 2                                       | 2                                        | 2                                 |
| Internet to meet sex partners                     | 3.1 (4/129)                         | 0.6 (1/174)                        | 1.2 (2/163)                             | 1.7 (2/116)                              | 1.6 (9/582)                       |
| Anonymous sex                                     | NA                                  | 10.3 (18/174)                      | 19.1 (31/162)                           | 22.9 (27/118)                            | 16.7 (76/454)                     |
| Methamphetamine use                               | 8.1 (10/123)                        | 1.7 (3/174)                        | 0.6 (1/163)                             | 2.3 (1/44)                               | 3.0 (15/504)                      |
| Exchange of money or drugs for sex                | 5.7 (8/140)                         | 1.2 (2/174)                        | 2.5 (4/163)                             | 2.6 (3/115)                              | 2.9 (17/592)                      |
| Incarceration of self or sex partner              | 26.4 (34/129)                       | 12.6 (22/174)                      | 9.2 (15/163)                            | 9.6 (11/115)                             | 14.1 (82/581)                     |
| Partner                                           |                                     |                                    |                                         |                                          |                                   |
| Seeking care because sex partner has STD          | 6.2 (9/145)                         | 17.3 (30/173)                      | 25.9 (42/162)                           | 29.4 (35/119)                            | 19.4 (116/599)                    |
| Sex with partner since being tested for gonorrhea | NA                                  | 18.6 (32/172)                      | 33.3 (54/162)                           | 14.9 (17/114)                            | 23.0 (103/448)                    |
| Sure partner received treatment                   | 53.3 (41/77)                        | 39.3 (68/173)                      | 54.9 (89/162)                           | 43.8 (49/112)                            | 47.1 (247/524)                    |
| Clinical history                                  |                                     |                                    |                                         |                                          |                                   |
| Symptomatic                                       | 95.2 (138/145)                      | 91.3 (158/173)                     | 71.6 (116/162)                          | 52.1 (62/119)                            | 79.1 (474/599)                    |
| If symptomatic, median days to seeking care (N)   | 3                                   | 4                                  | 3                                       | 3                                        | 3                                 |
| History of gonorrhea in last 12 months            | 18.9 (24/127)                       | 4.4 (6/136)                        | 8.7 (11/127)                            | 6.9 (8/116)                              | 9.7 (49/506)                      |
| Ever tested for HIV                               | 76.9 (103/134)                      | 76.7 (132/172)                     | 76.9 (123/160)                          | 68.1 (79/116)                            | 75.1 (437/582)                    |
| HIV-positive at time of visit                     | 1.5 (2/138)                         | 0.8 (1/124)                        | 0.9 (1/115)                             | 0.0 (0/77)                               | 0.9 (4/454)                       |

<sup>a</sup>Data for nine MSW in San Francisco were not included due to small numbers.

MSW = men who have sex with only women

STD = sexually transmitted disease

ER = emergency room

NA = not available

HIV = human immunodeficiency virus

**Table 4. Reported characteristics of MSM with gonorrhea interviewed in the STD Surveillance Network, 2006–2008<sup>a</sup>**

| Characteristic                                    | San Francisco<br>(n=104)<br>Percent (N) | Seattle<br>(n=113)<br>Percent (N) | Denver<br>(n=73)<br>Percent (N) | Minneapolis<br>(n=56)<br>Percent (N) | Total<br>(n=346)<br>Percent (N) |
|---------------------------------------------------|-----------------------------------------|-----------------------------------|---------------------------------|--------------------------------------|---------------------------------|
| Age (in years)                                    |                                         |                                   |                                 |                                      |                                 |
| ≤24                                               | 4.9 (5/103)                             | 41.6 (47/113)                     | 19.2 (14/73)                    | 10.7 (6/56)                          | 20.9 (72/345)                   |
| Race/ethnicity                                    |                                         |                                   |                                 |                                      |                                 |
| American Indian/Alaska Native                     | 1.0 (1/104)                             | 0.0 (0/113)                       | 0.0 (0/73)                      | 1.8 (1/56)                           | 0.6 (2/346)                     |
| Non-Hispanic Asian                                | 9.6 (10/104)                            | 1.8 (2/113)                       | 0.0 (0/73)                      | 1.8 (1/56)                           | 3.8 (13/346)                    |
| Non-Hispanic black                                | 3.9 (4/104)                             | 23.0 (26/113)                     | 5.5 (4/73)                      | 19.6 (11/56)                         | 13.0 (45/346)                   |
| Hispanic                                          | 15.4 (16/104)                           | 8.9 (10/113)                      | 16.4 (12/73)                    | 3.6 (2/56)                           | 11.6 (40/346)                   |
| Non-Hispanic white                                | 66.4 (69/104)                           | 44.3 (50/113)                     | 74.0 (54/73)                    | 71.4 (40/56)                         | 61.6 (213/346)                  |
| Other/multiracial                                 | 1.9 (2/104)                             | 5.3 (6/113)                       | 4.1 (3/73)                      | 1.8 (1/56)                           | 3.5 (12/346)                    |
| No answer                                         | 1.9 (2/104)                             | 16.8 (19/113)                     | 0.0 (0/73)                      | 0.0 (0/56)                           | 6.1 (21/346)                    |
| Practice setting                                  |                                         |                                   |                                 |                                      |                                 |
| ER/urgent care                                    | 0.0 (0/104)                             | 12.4 (14/113)                     | 17.8 (13/73)                    | 16.1 (9/56)                          | 10.4 (36/346)                   |
| Family planning/gynecology                        | 0.0 (0/104)                             | 12.4 (14/113)                     | 11.0 (8/73)                     | 0.0 (0/56)                           | 6.4 (22/346)                    |
| Hospital (non-ER)                                 | 9.6 (10/104)                            | 7.1 (8/113)                       | 8.2 (6/73)                      | NA                                   | 8.3 (24/290)                    |
| Jail/prison                                       | 0.0 (0/104)                             | 2.7 (3/113)                       | 0.0 (0/73)                      | 0.0 (0/56)                           | 0.9 (3/346)                     |
| Primary care                                      | 34.6 (36/104)                           | 37.2 (42/113)                     | 42.5 (31/73)                    | 73.2 (41/56)                         | 43.4 (150/346)                  |
| Other                                             | 53.9 <sup>b</sup> (56/104)              | 8.9 (10/113)                      | 20.6 (15/73)                    | 10.7 (6/56)                          | 25.1 (87/346)                   |
| No answer                                         | 1.9 (2/104)                             | 19.5 (22/113)                     | 0.0 (0/73)                      | 0.0 (0/56)                           | 6.9 (24/346)                    |
| Behavioral (past three months)                    |                                         |                                   |                                 |                                      |                                 |
| Median number of sex partners (N)                 | 3                                       | 1                                 | 2                               | 3                                    | 2                               |
| Internet to meet sex partners                     | 42.9 (42/98)                            | 26.5 (26/98)                      | 31.5 (23/73)                    | 44.6 (25/56)                         | 35.7 (116/325)                  |
| Anonymous sex                                     | 47.4 (46/97)                            | NA                                | 37.0 (27/73)                    | 30.4 (17/56)                         | 39.8 (90/226)                   |
| Methamphetamine use                               | 17.2 (17/99)                            | 8.3 (8/96)                        | 6.9 (5/72)                      | 16.1 (9/56)                          | 12.1 (39/323)                   |
| Exchange of money or drugs for sex                | 5.9 (6/101)                             | 5.7 (6/105)                       | 0.0 (0/73)                      | 0.0 (0/56)                           | 3.6 (12/335)                    |
| Incarceration of self or sex partner              | 2.0 (2/98)                              | 8.7 (9/104)                       | 6.9 (5/73)                      | 0.0 (0/56)                           | 4.8 (16/331)                    |
| Partner                                           |                                         |                                   |                                 |                                      |                                 |
| Seeking care because sex partner has STD          | 0.0 (0/101)                             | 5.4 (6/113)                       | 15.1 (11/73)                    | 5.6 (3/54)                           | 5.9 (20/341)                    |
| Sex with partner since being tested for gonorrhea | 31.9 (30/94)                            | NA                                | 20.6 (15/73)                    | 30.9 (17/55)                         | 27.9 (62/222)                   |
| Sure partner received treatment                   | 64.1 (50/78)                            | 63.8 (37/58)                      | 41.1 (30/73)                    | 50.9 (28/55)                         | 54.9 (145/264)                  |
| Clinical history                                  |                                         |                                   |                                 |                                      |                                 |
| Symptomatic                                       | 18.8 (19/101)                           | 86.7 (98/113)                     | 94.5 (69/73)                    | 83.9 (47/56)                         | 67.9 (233/343)                  |
| If symptomatic, median days to seeking care (N)   | NA                                      | 3                                 | 3                               | 3                                    | 3                               |
| History of gonorrhea in last 12 months            | 10.4 (10/96)                            | 17.2 (17/99)                      | 14.6 (7/48)                     | 6.4 (3/47)                           | 12.8 (37/290)                   |
| Ever tested for HIV                               | 99.0 (95/96)                            | 83.7 (87/104)                     | 91.8 (67/73)                    | 100.0 (53/53)                        | 92.6 (302/326)                  |
| HIV-positive at time of visit                     | 47.3 (44/93)                            | 7.8 (7/90)                        | 34.9 (23/66)                    | 26.0 (13/50)                         | 29.1 (87/299)                   |

<sup>a</sup>Data for 17 MSM in Richmond, Virginia, were not included due to small numbers.<sup>b</sup>"Other" in San Francisco included a gay men's health center.

NA = not available

MSM = men who have sex with men

STD = sexually transmitted disease

ER = emergency room

NA = not available

HIV = human immunodeficiency virus

San Francisco, 12.5% of MSM in Minneapolis, 5.5% of MSM in Denver, and 5.3% of MSM in Seattle. Pharyngeal infection was reported among 40.4% of MSM in San Francisco, 3.5% of MSM in Seattle, 2.7% of MSM in Denver, and 1.8% of MSM in Minneapolis. It was not possible to assess the underlying differences in screening practices among areas in this SSuN database (data not shown).

Overall, only 5.9% of MSM sought care because a sex partner had an STD. A total of 27.9% of MSM had had sex since being tested for gonorrhea, yet only 54.9% were sure their partner had received treatment (Table 4).

Overall, both anonymous sex and use of the Internet to meet sex partners were more likely to be reported at all sites (39.8% and 35.7%, respectively) compared with women and MSW. Reported methamphetamine use was also high in San Francisco and Minneapolis (17.2% and 16.1%, respectively). Overall, incarceration of self or sex partner (4.8%) and exchange of money and drugs for sex (3.6%) were rarely reported.

## DISCUSSION

The SSuN project provides critical epidemiologic data to supplement limited data that are routinely collected from passive case-based national surveillance. Data presented in this study suggest that in the metropolitan areas that participate in the SSuN, two overlapping epidemics of gonorrhea are occurring simultaneously in minority populations: one among young, black heterosexuals and another among older, mostly white MSM. Identifying these concurrent epidemics from nationally reportable data would not have been possible, as gender of sex partners is not routinely collected or reported to CDC.

In SSuN interviews, heterosexual gonorrhea patients were significantly more likely than MSM to report recent incarceration of themselves or their partners ( $p < 0.0001$ , data not shown), whereas MSM reported much higher frequencies of methamphetamine use ( $p < 0.0001$ ), use of the Internet to meet sex partners ( $p < 0.0001$ ), and anonymous sex ( $p < 0.0001$ ) than did heterosexual gonorrhea patients. HIV co-infections were rare among heterosexual SSuN patients; however, more than one in four MSM with gonorrhea reported being co-infected with HIV ( $p < 0.0001$ ). MSM were significantly more likely to report having been tested for HIV ( $p < 0.0001$ ). ER providers diagnosed a greater proportion of women and heterosexual men than MSM ( $p < 0.0001$ ), and symptomatic women waited longer than symptomatic men before seeking care ( $p < 0.0001$ ).

Such findings suggest that a one-size-fits-all approach

to gonorrhea prevention and control efforts is likely to be ineffective. A health department responsible for a population in which patients with gonorrhea are primarily women and heterosexual men may want to ensure that prevention, screening, and treatment services are available and acceptable to populations that are young and black. If services are either not available or acceptable to these populations, then health departments may need to identify means of reaching these populations. For example, efforts to increase screening and treatment in incarceration facilities may have a greater impact on a young minority heterosexual epidemic than an older MSM epidemic. Given that more than one-quarter of heterosexuals with gonorrhea were diagnosed in ER and urgent care settings, targeted screening of adolescents seeking care in these settings should be considered.<sup>8</sup>

In contrast, health departments with a significant population of MSM with gonorrhea should use different strategies for the prevention, screening, and treatment of MSM. For example, to reach MSM, health departments could consider screening at known MSM meeting venues, using the Internet to target prevention messages to MSM who are meeting partners on the Internet, or working with substance abuse programs to provide prevention counseling messages or gonorrhea screening for their clients. Ensuring that extragenital testing is widely available and STD screening is integrated into routine HIV care may be useful activities for local gonorrhea-control programs.

Health departments may have a combination of heterosexual and MSM epidemics. In an ideal world with unlimited resources, gonorrhea-control efforts could be rolled out widely for both populations. However, given that gonorrhea is rarely a health priority, most health departments have resources for only a limited number of interventions. To target control measures to reduce health disparities, it is necessary to have information on which populations to target. SSuN data suggest that gender of sex partner is a fundamentally important category of information for understanding a gonorrhea epidemic; all health departments are encouraged to more routinely collect data on gender of sex partners through case-based surveillance.

Currently, national case-report data for gonorrhea do not routinely include gender of sex partner. In 2007, gender of sex partner was unknown for 91.9% of gonorrhea morbidity reports received at CDC (Unpublished data, CDC, Division of STD Prevention, 2010). It is possible that health departments have this information available locally but are not transmitting it nationally. However, it is more likely that gender of sex partner is not recorded routinely on reporting forms in many

states either because the form does not allow for the collection of such data or the data are not provided by the reporting clinician or laboratory. Many health departments rely heavily on laboratory reports, and unlike traditional demographic information (e.g., age, gender, and race/ethnicity), gender of sex partner may not be collected routinely for administrative purposes. For syphilis reporting, many health departments overcome this limitation by interviewing reported patients. However, given the significantly larger case burden for gonorrhea, few health departments have the resources to routinely interview patients with gonorrhea. Through supplemental surveillance platforms such as the SSuN, additional epidemiologic information can be collected outside of the traditional, passive case-based surveillance system to better address health disparities. Several innovative approaches to enhance gonorrhea surveillance, such as the use of geocoding, spatial analysis, and tablet personal computers for interviewing, have been explored and described in a variety of settings.<sup>9,10</sup>

### Limitations

This study was subject to several limitations. As similar projects have found, successfully locating and interviewing patients with gonorrhea can be challenging.<sup>11,12</sup> SSuN sites were able to successfully interview only approximately one out of every five patients selected for interview, despite determined efforts to improve the response rate. All SSuN sites attempted to contact patients at least three and sometimes up to 10 times through a variety of methods, including different times of day and different days of the week. In the overwhelming majority of cases, the reason for non-interview was that the patient could not or refused to be located by phone (77.5%). Of note, of those patients who were successfully contacted by SSuN staff, only 3.7% of patients declined to be interviewed, 1.4% quit before the interview was completed, and 1.0% had a language barrier to being interviewed. Although interviews were generally conducted in English, interviewers in at least three sites were able to conduct interviews in Spanish, as necessary.

Informal discussions with SSuN interviewers suggest that poor contact information was a frequent barrier, especially among case reports originating from laboratories. Poor contact information could be the result of incomplete collection of data by health personnel; intentional provision of invalid contact information on the part of a patient (to avoid association with the stigma of having an STD); or unintentionally provided invalid contact information related to young age, pov-

erty, or other factors associated with the economic or social instability of many patients with gonorrhea.<sup>13-15</sup>

The low response rate encountered by the SSuN also introduced a potential response bias to the analysis. This response bias was examined through comparison of age and race for SSuN-interviewed patients with patients who were selected but could not be interviewed for any reason. Compared with nonrespondents, SSuN participants were more likely to be white, and female participants were more likely to be young. In addition, there were likely other differences between the two groups that could not be assessed. Given the paucity of population-based epidemiologic data on gonorrhea in the U.S., however, these data are still informative and useful for guiding public health interventions to control gonorrhea to an extent not possible through routine case-report data.

An additional limitation to SSuN methodology and resultant data was that the gonorrhea surveillance activity in SSuN Cycle 1 described in this article was limited to five metropolitan areas that were not randomly selected. Therefore, SSuN patient data should not be construed as representing all non-STD clinic patients with gonorrhea in the U.S. SSuN Cycle 2 is currently underway in 12 geographically diverse metropolitan areas that account for more than 20% of all U.S. gonorrhea morbidity and is, therefore, likely to improve how well SSuN data reflect the gonorrhea epidemic across the U.S.

SSuN collaborators developed a common protocol used by all sites for the collection of supplemental epidemiologic data. However, SSuN surveillance activities were integrated into existing systems, not implemented as a formal, independent research protocol. As a result, each SSuN site had its own local protocols, and SSuN activities were implemented in the context of existing diagnosis, treatment, and prevention interventions. For example, screening of the pharynx and rectum of patients reporting exposure at these sites is widely practiced in San Francisco, thus providing one possible explanation for why a greater proportion of MSM from San Francisco had reported pharyngeal and rectal gonorrhea.<sup>16</sup> Another example of the possible effect of using data from a surveillance rather than a research activity can be seen in the widely varying proportion of women presenting with symptoms (29.3% in San Francisco to 80.9% in Richmond), as the proportion of symptomatic women will be strongly affected by how much gonorrhea screening of asymptomatic women is conducted in the clinic.

To ensure a common definition across all SSuN sites for the sexual orientation of patients, a three-month



time frame for elicitation of the sex of sexual partners was used. However, male patients who had sex with a man more than three months prior to the interview or who did not report being gay or bisexual would, therefore, be classified for this analysis as MSW, thus potentially introducing a classification bias.

## CONCLUSIONS

Despite these limitations, the data obtained from the SSuN provide information that cannot be obtained through routine surveillance for targeting of gonorrhea-control activities in five metropolitan areas. The analysis shows the differences and similarities among the gonorrhea epidemic in five different areas. In addition, the SSuN experience is useful for providing a better understanding of how to collect data on patients reported with gonorrhea. The data tell a tale of two different epidemics among minority populations: one of a young, black, heterosexual epidemic with frequently reported incarceration, and another of an older, white, MSM epidemic with high levels of HIV coinfection and high-risk sexual behaviors. Such findings suggest that a one-size-fits-all approach to gonorrhea may not be effective in reducing health disparities. Rather, health departments should improve data collection on gender of sex partners and other key risk behaviors to allow for targeting of gonorrhea-control interventions to the most affected populations.

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No protocol approval was needed for this study because data were obtained from existing sources. The SSuN was determined by CDC to be a non-research public health activity to control disease and conduct surveillance. The findings and conclusions in this article are those of the authors and do not necessarily represent the official position of CDC.

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# Using Disability-Adjusted Life Years to Assess the Burden of Disease and Injury in Rhode Island

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## ABSTRACT

**Objectives.** Disability-adjusted life years (DALYs) measure the burden of disease and injury in a population. We tested the feasibility of calculating DALYs to assess the burden of disease and injury in Rhode Island (RI).

**Methods.** We computed DALYs for the 2008 RI population using methods developed by the World Health Organization, Harvard University, and the World Bank. DALYs are a composite measure that sum years of life lost (YLLs) due to premature mortality with years lived with disability (YLDs). We calculated crude mortality, YLLs, YLDs, and DALYs for 90 major health conditions for RI and stratified them by gender and age. Calculations for YLLs and YLDs were based on five-year averages. We compared our results with U.S. and Los Angeles County, California, estimates.

**Results.** A DALYs ranking produces a different picture of RI's disease and injury burden than does mortality-based ranking. Of 90 major health conditions assessed for RI, six of the top 10 causes for mortality and DALYs were the same, but were ranked differently: ischemic heart disease, cerebrovascular disease, Alzheimer dementia and other dementias, trachea/bronchus/lung cancer, chronic obstructive pulmonary disease, and diabetes mellitus. These six conditions accounted for 59% of deaths but only 35% of DALYs. Causes and rank orders for DALYs differed between males and females and among age groups.

**Conclusions.** Including nonfatal health conditions in an assessment of population health provides a different picture than traditional mortality-based assessments. This study demonstrates the feasibility and constraints of using DALYs to assess the burden of disease and injury at the state level.

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Mortality data have been used traditionally to identify a population's most important health problems.<sup>1</sup> However, falling death rates often mean people are living longer but with years of illness and disability. Mortality measures provide incomplete information about overall population health, necessitating the development of alternate summary measures.<sup>1,2</sup> The World Health Organization (WHO), Harvard University, and the World Bank introduced disability-adjusted life years (DALYs) in the Global Burden of Disease (GBD) study.<sup>3,4</sup> DALYs reflect the years of life lost (YLLs) to premature death and the years spent in unhealthy states, combining the impacts of mortality and disability.

DALYs are a "health gap" measure that represents the gap between the current health status of a population and one in which everyone lives into old age free of disease and injury.<sup>5,6</sup> It includes the impact of usually nonfatal conditions, such as alcohol use, mental disorders, arthritis, and injuries, and provides a different picture of population health than traditional mortality-based assessments.

Several studies have implemented DALYs and published disease and injury burden reports for countries and subnational entities,<sup>1-3,5,7</sup> including for the United States<sup>2</sup> and for Los Angeles (LA) County, California.<sup>3</sup> In this study, we applied DALYs to the Rhode Island (RI) population using the GBD study methods.<sup>4</sup> We estimated DALYs for major health conditions, compared DALYs results with traditional mortality measures, and assessed the benefits and limitations of estimating DALYs at the state level. To our knowledge, RI is the first U.S. state to attempt the use of DALYs to evaluate the burden of disease and injury at the state level.

## METHODS

We used methods developed by WHO, Harvard University, and the World Bank to compute DALYs<sup>4</sup> for the 2008 RI population. DALYs are a composite measure of years of healthy life lost due to both fatal and nonfatal conditions. They are a summation of YLLs due to premature mortality and years lived with disability (YLDs), adjusted for duration and severity, due to specific conditions. One DALY equates to one year of healthy life lost.<sup>1-3</sup> Crude mortality, YLLs, YLDs, and DALYs for 90 major health conditions were calculated overall and stratified by gender and seven age groups. RI's small population size and low proportion of racial/ethnic minority groups prevented us from stratifying by race/ethnicity as other studies have done.

We calculated YLLs using RI mortality data for all conditions, while YLDs were calculated using RI cancer registry data, and disease and injury parameters

including incidence estimates, average duration, and disability severity weights developed by Harvard University,<sup>2</sup> the World Bank, and WHO.<sup>4,8</sup> Denominators were based on 2008 RI census population estimates. The 90 health conditions used were disease and injury categories defined in the U.S. Burden of Disease and Injury (USBODI) study.<sup>2</sup>

## Data sources

Reflecting RI's small population (about one million), the number of RI deaths for many causes is small and can fluctuate from year to year. To reduce error due to such variation, we used five years (2004–2008) of RI death registry data for estimates of deaths and five years (2004–2008) of RI cancer registry data for estimates of cancer incidence. We used 2008 census estimates for population denominators.

We used RI death data to calculate YLLs for all 90 conditions in our study. To calculate YLDs for 24 cancers, we used RI cancer registry data and obtained other parameters (e.g., disability weights, duration of disability, and age of onset of disability) from the USBODI study. Because reliable state disease incidence data—which are needed to calculate YLDs—were lacking for conditions other than cancer, we used U.S. incidence estimates and other needed parameters for 31 conditions from the USBODI study. However, the USBODI study did not provide incidence data or one of the other parameters needed to calculate YLDs for the remaining 35 conditions.<sup>2</sup> To address this problem, we adopted the method used by the USBODI study of applying age- and gender-specific YLD-to-YLL ratios for Established Market Economics countries provided in the GBD study<sup>4</sup> to calculate YLDs. Figure 1 indicates the data sources used to calculate YLDs for the 90 conditions in our study.

## Years of life lost (YLLs)

YLLs capture the loss of life associated with premature death due to a specific cause occurring at a particular age. One YLL is calculated as follows:

$$YLL = \frac{KCe^{ra}}{(r+\beta)^2} \left[ e^{-(r+\beta)(L+a)} [-(r+\beta)(L+a)-1] - e^{-(r+\beta)a} [-(r+\beta)a-1] \right] + \frac{1-K}{r} (1-e^{-rL})^4$$

- $K$  = age-weighting modulation factor
- $C$  = a necessary adjustment constant due to unequal age weights
- $r$  = discount rate
- $a$  = age at death
- $\beta$  = age-weighting parameter
- $L$  = the standard expectation of life at age  $a$

**Figure 1. Rhode Island burden of disease and injury study (YLDs) data sources**

| Data source                                                                         | Condition                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|-------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Rhode Island Cancer Registry 2004–2008 (24 conditions) <sup>a</sup>                 | Mouth and oropharynx cancer; esophagus cancer; stomach cancer; colon and rectum cancer; liver cancer; pancreas cancer; trachea/bronchus/lung cancer; melanoma cancer; nonmelanoma skin cancer; breast cancer; cervix uteri cancer; corpus uteri cancer; ovary cancer; prostate cancer; bladder cancer; kidney and renal pelvis cancer; brain cancer; Hodgkin's disease; non-Hodgkin's lymphoma; multiple myeloma; lymphocytic (acute, chronic, and other) leukemias; myelocytic and monocytic leukemias; other leukemias; other neoplasms                                                                                                                                                                                                                                                                                         |
| U.S. Burden of Disease and Injury study (31 conditions) <sup>b</sup>                | Tuberculosis, HIV/AIDS, diabetes mellitus, unipolar major depression, bipolar disorder, schizophrenia, epilepsy, alcohol use, Alzheimer dementia and other dementias, Parkinson's disease, multiple sclerosis, drug use, obsessive-compulsive disorders, panic disorder, ischemic heart disease, cerebrovascular disease, asthma, rheumatoid arthritis, osteoarthritis, anorectal atresia, oral clefts, oesophageal atresia, Down syndrome, congenital heart anomalies, spina bifida, road traffic accidents, poisonings, drownings, suicide and self-inflicted injuries, homicide and violence, posttraumatic stress disorder                                                                                                                                                                                                    |
| YLD/YLL ratios from the Global Burden of Disease study (35 conditions) <sup>c</sup> | Sexually transmitted diseases excluding HIV, diarrheal diseases, childhood-cluster diseases, bacterial meningitis and meningococcaemia, hepatitis B and hepatitis C, septicemia, lower respiratory infections, upper respiratory infections, otitis media, perinatal conditions, protein-energy malnutrition, small intestine cancer, nutritional/endocrine disorders, sense organ diseases, rheumatic heart disease, inflammatory heart diseases, valvular disorders, aortic aneurysm, hypertension and hypertensive heart disease, pulmonary embolism, chronic obstructive pulmonary disease, oesophagus, peptic ulcer disease, cirrhosis of the liver, appendicitis, genitourinary diseases, skin diseases, anencephaly, renal agenesis, oral conditions, falls, fires, accidental firearms, other unintentional injuries, war |

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<sup>c</sup>Murray CJL, Lopez AD, editors. The global burden of disease: a comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected to 2020. Vol 10. Cambridge (MA): Harvard University Press; 1996.

YLDs = years lived with disability

YLLs = years of life lost

HIV = human immunodeficiency virus

AIDS = acquired immunodeficiency syndrome

For standard YLLs used in the GBD study,<sup>3</sup>  $K=1$ ,  $C=0.1658$ ,  $r=0.03$ , and  $\beta=0.04$ .

Standard life tables representing the maximum remaining life expectancy at each age, for males and females, were adopted from the GBD study.<sup>4</sup> These standard life tables have been used by others calculating DALYs for the U.S. population.<sup>1-3</sup>

To calculate the number of YLLs associated with a condition, the number of YLLs per death at each age and gender must be multiplied by the number of deaths at each age and gender, and then summed across all ages and genders.

Total YLLs =  $\Sigma[(\text{Number of deaths due to cause } i \text{ by age and gender}) \times \text{YLL}]^4$

Causes of death during 2004–2008 for all people who had their usual place of residence in RI were grouped into 90 disease and injury categories. The underlying cause of death was denoted using the International Classification of Diseases, 10th Revision codes.<sup>9</sup>

#### Years lived with disability (YLDs)

The calculation of YLDs requires estimates of disease and injury incidence, average duration of associated disability, and disability weight.<sup>4,10</sup> A disability weight indicates the average severity of any mental or physical disability associated with each disease or injury.<sup>1,3</sup> Disability weights are expressed as a number on a scale from 0 to 1, with 0 representing ideal health and 1 representing death. Estimation of disability weights were based on the person trade-off method, which is explained in detail elsewhere. Duration estimates are the average duration for each disabling sequelae associated with each disease or injury.<sup>4</sup> One YLD is calculated as follows:

$$YLD = D \left\{ \frac{KCe^{ra}}{(r + \beta)^2} \left[ e^{-(r + \beta)(L + a)} [-(r + \beta)(L + a) - 1] - e^{-(r + \beta)a} [-(r + \beta)a - 1] \right] + \frac{1 - K}{r} (1 - e^{-rL}) \right\}^4$$

- $D$  = disability weight
- $K$  = age-weighting modulation factor

- $C$  = a necessary adjustment constant due to unequal age weights
- $r$  = discount rate
- $a$  = age of onset of the disability
- $\beta$  = age-weighting parameter
- $L$  = duration of disability

For standard YLDs used in the GBD study,<sup>4</sup>  $K=1$ ,  $C=0.1658$ ,  $r=0.03$ , and  $\beta=0.04$ .

To calculate the number of YLDs associated with a condition, the number of YLDs lost per incident at each age and gender must be multiplied by the number of incidents at each age and gender, and then summed across all ages and genders.

Total YLDs =  $\Sigma[(\text{Number of incidents due to cause } i \text{ by age and gender}) \times \text{YLD}]^4$

### Disability-adjusted life years (DALYs)

DALYs are a composite measure of mortality and disability attributed to a specific cause equal to the summation of YLLs due to premature death and YLDs due to the specific cause.<sup>1-4,6</sup> We calculated DALYs for each of 90 health conditions, and for each condition stratified by gender and seven age groups, based on the formula:

$$\text{DALYs} = \text{YLLs} + \text{YLDs}^{10}$$

All calculations were performed using Microsoft® Excel and SAS® version 9.1.<sup>11</sup>

## RESULTS

Table 1 displays the 10 leading causes of DALYs, deaths, YLLs, and YLDs. The RI estimated burden in 2008 due to 90 disease and injury categories was 95,395 DALYs and 8,108 deaths. When DALYs were compared with mortality as a measure of disease and injury burden, the top 10 DALYs accounted for 51% of all DALYs, while the top 10 causes of death accounted for 69% of all deaths. Six causes of DALYs and death were the same, though their ranking and proportion of burden differed (e.g., ischemic heart disease [IHD] was the leading cause of both death and DALYs but accounted for a greater proportion of deaths than of DALYs [28% vs. 12%]). Alzheimer dementia and other dementias, trachea/bronchus/lung cancer, chronic obstructive pulmonary disease (COPD), and diabetes mellitus decreased in rank when going from cause of death to cause of DALYs, while cerebrovascular disease increased in rank. Cerebrovascular disease, dementia, and COPD also appeared among the top 10 causes of YLLs and YLDs.

### Patterns by gender

Table 2 presents the leading causes of DALYs by gender. Males had a higher number of DALYs from all causes (48,562) than did females (46,833). However, the burden for the top 10 DALYs for females (26,769 or 57% of total female DALYs) exceeded that for males (23,891 or 49% of total male DALYs). IHD, the leading cause of DALYs for both genders, accounted for about 13% of DALYs for males and 10% of DALYs for females. Cerebrovascular disease, lung cancer, dementia, depression, osteoarthritis, and COPD dominated the list of major causes in both groups, though they were ranked differently and each was a higher proportion of all DALYs for females than for males, with the exception of lung cancer. Breast cancer, genitourinary diseases, and asthma were among the top 10 leading causes of DALYs for females but not for males. Drug use, road traffic accidents, and alcohol use were among the top 10 leading causes of DALYs for males but not for females.

### Patterns by age group

Table 3 presents the leading causes of DALYs by age group. More than half (66%) of the total number of DALYs occurred in adults aged 45 years and older. Most of the remaining burden was distributed between those aged 15–24 years (11%) and 25–44 years (17%), while the younger age groups—those aged 0–4 years and 5–14 years—accounted for only 4% and 2% of the total burden, respectively (data not shown).

Leading causes of DALYs varied by age group. For the three oldest age groups (45–64, 65–74, and  $\geq 75$  years of age), leading causes were primarily chronic disease conditions. IHD, the leading cause of DALYs, accounted for 15% of DALYs for those aged 45–64 years, 16% of DALYs for those aged 65–74 years, and 20% of DALYs for those  $\geq 75$  years of age. Five other chronic conditions were common to the three age groups, though they were ranked differently: lung cancer, cerebrovascular disease, osteoarthritis, COPD, and nutritional/endocrine disorders. The leading causes of DALYs for those aged 15–24 and 25–44 years were primarily mental and behavior-related conditions. Depression, drug use, and alcohol use were common to both age groups. Road traffic accidents, panic disorder, homicide, and obsessive-compulsive disorder were among the leading causes of DALYs for those aged 15–24 years, while posttraumatic stress disorder, poisonings, suicide, and human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) were among the leading causes of DALYs for those aged 25–44 years. Due to the small number of deaths and hospitalizations among children, only the top



**Table 1. Ten leading causes of burden of disease and injury, based on various measures: Rhode Island, 2008**

| Rank                         | DALYs                                  |                      | Crude mortality                        |                      | YLLs                                   |                     | YLDs                                   |                     |
|------------------------------|----------------------------------------|----------------------|----------------------------------------|----------------------|----------------------------------------|---------------------|----------------------------------------|---------------------|
|                              | Cause                                  | DALYs<br>N (percent) | Cause                                  | Death<br>N (percent) | Cause                                  | YLLs<br>N (percent) | Cause                                  | YLDs<br>N (percent) |
| 1                            | Ischemic heart disease                 | 11,267 (11.8)        | Ischemic heart disease                 | 2,256 (27.8)         | Ischemic heart disease                 | 9,971 (20.9)        | Unipolar major depression              | 5,992 (12.5)        |
| 2                            | Unipolar major depression              | 6,001 (6.3)          | Alzheimer dementia and other dementias | 702 (8.7)            | Trachea/bronchus/ lung cancer          | 4,248 (8.9)         | Osteoarthritis                         | 4,207 (8.8)         |
| 3                            | Cerebrovascular disease                | 5,653 (5.9)          | Trachea/bronchus/ lung cancer          | 639 (7.9)            | COPD                                   | 2,079 (4.4)         | Cerebrovascular disease                | 3,637 (7.6)         |
| 4                            | Alzheimer dementia and other dementias | 5,402 (5.7)          | Cerebrovascular disease                | 469 (5.8)            | Cerebrovascular disease                | 2,016 (4.2)         | Alzheimer dementia and other dementias | 3,526 (7.4)         |
| 5                            | Trachea/bronchus/ lung cancer          | 4,540 (4.8)          | COPD                                   | 451 (5.6)            | Alzheimer dementia and other dementias | 1,876 (3.9)         | Drug use                               | 2,363 (4.9)         |
| 6                            | COPD                                   | 4,281 (4.5)          | Genitourinary diseases                 | 260 (3.2)            | Road traffic accidents                 | 1,780 (3.7)         | Asthma                                 | 2,212 (4.6)         |
| 7                            | Osteoarthritis                         | 4,218 (4.4)          | Lower respiratory infections           | 251 (3.1)            | Suicide and self-inflicted injuries    | 1,699 (3.6)         | COPD                                   | 2,202 (4.6)         |
| 8                            | Drug use                               | 2,435 (2.6)          | Diabetes mellitus                      | 239 (2.9)            | Poisonings                             | 1,616 (3.4)         | Bipolar disorder                       | 1,488 (3.1)         |
| 9                            | Road traffic accidents                 | 2,315 (2.4)          | Colon and rectum cancer                | 205 (2.5)            | Diabetes mellitus                      | 1,489 (3.1)         | Alcohol use                            | 1,325 (2.8)         |
| 10                           | Diabetes mellitus                      | 2,315 (2.4)          | Breast cancer                          | 157 (1.9)            | Breast cancer                          | 1,288 (2.7)         | Schizophrenia                          | 1,313 (2.8)         |
| Total from the top 10 causes |                                        | 48,426 (50.8)        |                                        | 5,629 (69.4)         |                                        | 28,061 (58.9)       |                                        | 28,265 (59.2)       |
| Total from the 90 causes     |                                        | 95,395 (100.0)       |                                        | 8,108 (100.0)        |                                        | 47,643 (100.0)      |                                        | 47,752 (100.0)      |

DALYs = disability-adjusted life years

YLLs = years of life lost

YLDs = years lived with disability

COPD = chronic obstructive pulmonary disease

**Table 2. Ten leading causes of burden of disease and injury, by gender: Rhode Island, 2008**

| Rank                         | Males                                  |                      | Females                                |                      |
|------------------------------|----------------------------------------|----------------------|----------------------------------------|----------------------|
|                              | Cause                                  | DALYs<br>N (percent) | Cause                                  | DALYs<br>N (percent) |
| 1                            | Ischemic heart disease                 | 6,381 (13.1)         | Ischemic heart disease                 | 4,886 (10.4)         |
| 2                            | Cerebrovascular disease                | 2,472 (5.1)          | Unipolar major depression              | 4,039 (8.6)          |
| 3                            | Trachea/bronchus/lung cancer           | 2,327 (4.8)          | Alzheimer dementia and other dementias | 3,394 (7.2)          |
| 4                            | Alzheimer dementia and other dementias | 2,008 (4.1)          | Cerebrovascular disease                | 3,181 (6.8)          |
| 5                            | Unipolar major depression              | 1,962 (4.0)          | COPD                                   | 2,639 (5.6)          |
| 6                            | Osteoarthritis                         | 1,926 (4.0)          | Osteoarthritis                         | 2,292 (4.9)          |
| 7                            | Drug use                               | 1,878 (3.9)          | Trachea/bronchus/lung cancer           | 2,213 (4.7)          |
| 8                            | Road traffic accidents                 | 1,787 (3.7)          | Breast cancer                          | 1,659 (3.5)          |
| 9                            | COPD                                   | 1,642 (3.4)          | Genitourinary diseases                 | 1,241 (2.7)          |
| 10                           | Alcohol use                            | 1,508 (3.1)          | Asthma                                 | 1,226 (2.6)          |
| Total from the top 10 causes |                                        | 23,891 (49.2)        | 26,769 (57.2)                          |                      |
| Total from the 90 causes     |                                        | 48,562 (100.0)       | 46,833 (100.0)                         |                      |

DALYs = disability-adjusted life years

COPD = chronic obstructive pulmonary disease

four causes of DALYs could be estimated for children aged 0–4 and 5–14 years. Perinatal conditions, which are unique to infants, accounted for 32% of DALYs, while congenital heart anomalies accounted for 30% of DALYs in children aged 0–4 years. For children aged 5–14 years, asthma accounted for 40%, and road traffic accidents accounted for 12% of all DALYs.

## DISCUSSION

The 10 leading causes of DALYs for RI in 2008 were compared with published DALYs assessments for the U.S. in 1996<sup>2</sup> and LA County in 1997.<sup>3</sup> Despite the 10-year gap between the calculation of DALYs for these U.S. entities, there were several commonalities (Figure 2). IHD was the leading cause of DALYs for each of these entities, and seven conditions appeared in the top 10 causes of DALYs for each, though in different rank order: depression, cerebrovascular disease, lung cancer, COPD, osteoarthritis, road traffic accidents, and diabetes mellitus. RI's top 10 causes of DALYs also included dementia and drug use, the U.S. top 10 causes of DALYs included alcohol use and HIV, and the LA County top 10 causes of DALYs included alcohol use and homicide/violence.

Alcohol use was the 19th leading cause of DALYs in RI (data not shown). Although alcohol use rates in RI are high,<sup>12</sup> RI's alcohol use mortality rate during 2004–2008 was almost half the national rate in 1996

(1.43 per 100,000 population vs. 2.52 per 100,000 population<sup>2</sup>). This figure may explain why alcohol use is not among the top 10 causes of DALYs for RI as it is in the U.S.

HIV was not a leading cause of DALYs in RI as it was in the U.S.<sup>2</sup> (HIV was the 33rd leading cause of DALYs in RI [data not shown].) This RI vs. U.S. comparison must take into account the advances that have been made during the past 20 years in clinical therapy and antiretroviral medications<sup>13</sup> in the treatment of HIV/AIDS. Our DALYs calculations used RI HIV/AIDS mortality data for 2004–2008, while the U.S. HIV/AIDS DALYs calculations were based on mortality data for the U.S. in 1996.<sup>1,2</sup> Starting in 1994, the number of RI AIDS deaths declined steadily and stabilized in 1998.<sup>13</sup> National HIV/AIDS deaths began declining in 1996 and stabilized in 1998.<sup>14</sup> The RI HIV/AIDS mortality rate for 2004–2008 (2.38 per 100,000 population) was much lower than that for the U.S. in 1996 (7.99 per 100,000 population<sup>2</sup>). RI's low HIV/AIDS mortality rate during the period 2004–2008 can explain why HIV was not among the top 10 causes of DALYs for RI.

Seven causes of DALYs for males and females were the same, while three differed between the genders (Table 2). Alcohol use, a major cause of cirrhosis,<sup>15,16</sup> accounted for 3% of DALYs for males. The more common use of alcohol among men has been documented by others.<sup>16,17</sup> Depression was the second leading cause of DALYs among women. Women are much more likely

**Table 3. Ten leading causes of burden of disease and injury, by age group: Rhode Island, 2008**

| Rank                           | 0–4 years                  |                      | 5–14 years                     |                      | 15–24 years                    |                      | 25–44 years                         |                      |
|--------------------------------|----------------------------|----------------------|--------------------------------|----------------------|--------------------------------|----------------------|-------------------------------------|----------------------|
|                                | Cause                      | DALYs<br>N (percent) | Cause                          | DALYs<br>N (percent) | Cause                          | DALYs<br>N (percent) | Cause                               | DALYs<br>N (percent) |
| 1                              | Perinatal conditions       | 1,133 (32.2)         | Asthma                         | 806 (39.9)           | Drug use                       | 1,577 (14.6)         | Unipolar major depression           | 3,341 (20.5)         |
| 2                              | Congenital heart anomalies | 1,069 (30.4)         | Road traffic accidents         | 238 (11.8)           | Road traffic accidents         | 1,177 (10.9)         | Poisonings                          | 899 (5.5)            |
| 3                              | Down syndrome              | 283 (8.0)            | Schizophrenia                  | 142 (7.0)            | Schizophrenia                  | 1,042 (9.6)          | Ischemic heart disease              | 857 (5.3)            |
| 4                              | Asthma                     | 263 (7.5)            | Epilepsy                       | 140 (6.9)            | Unipolar major depression      | 985 (9.1)            | Suicide and self-inflicted injuries | 752 (4.6)            |
| 5                              | NC <sup>a</sup>            |                      | NC <sup>a</sup>                |                      | Bipolar disorder               | 974 (9.0)            | Drug use                            | 729 (4.5)            |
| 6                              | NC <sup>a</sup>            |                      | NC <sup>a</sup>                |                      | Alcohol use                    | 710 (6.6)            | Cerebrovascular disease             | 625 (3.8)            |
| 7                              | NC <sup>a</sup>            |                      | NC <sup>a</sup>                |                      | Panic disorder                 | 691 (6.4)            | HIV/AIDS                            | 620 (3.8)            |
| 8                              | NC <sup>a</sup>            |                      | NC <sup>a</sup>                |                      | Asthma                         | 650 (6.0)            | Alcohol use                         | 560 (3.4)            |
| 9                              | NC <sup>a</sup>            |                      | NC <sup>a</sup>                |                      | Homicide and violence          | 545 (5.0)            | Posttraumatic stress disorder       | 541 (3.3)            |
| 10                             | NC <sup>a</sup>            |                      | NC <sup>a</sup>                |                      | Obsessive-compulsive disorders | 399 (3.7)            | Osteoarthritis                      | 534 (3.3)            |
| Total from the top four causes |                            | 2,747 (78.1)         | Total from the top four causes | 1,326 (65.6)         | Total from the top 10 causes   | 8,749 (80.9)         | Total from the top 10 causes        | 9,458 (58.0)         |
| Total from the 90 causes       |                            | 3,515 (100.0)        | Total from the 90 causes       | 2,020 (100.0)        | Total from the 90 causes       | 10,816 (100.0)       | Total from the 90 causes            | 16,319 (100.0)       |

continued on p. 300

**Table 3 (continued). Ten leading causes of burden of disease and injury, by age group: Rhode Island, 2008**

| Rank                         | 45–64 years                     |                      |  | 65–74 years                            |                      |                | ≥75 years                              |                      |                |
|------------------------------|---------------------------------|----------------------|--|----------------------------------------|----------------------|----------------|----------------------------------------|----------------------|----------------|
|                              | Cause                           | DALYs<br>N (percent) |  | Cause                                  | DALYs<br>N (percent) |                | Cause                                  | DALYs<br>N (percent) |                |
| 1                            | Ischemic heart disease          | 4,328 (14.7)         |  | Ischemic heart disease                 | 2,078 (15.6)         |                | Ischemic heart disease                 | 3,995 (20.0)         |                |
| 2                            | Trachea/bronchus/lung cancer    | 2,304 (7.8)          |  | COPD                                   | 1,302 (9.8)          |                | Alzheimer dementia and other dementias | 3,495 (17.5)         |                |
| 3                            | Cerebrovascular disease         | 2,103 (7.2)          |  | Trachea/bronchus/lung cancer           | 1,246 (9.4)          |                | Cerebrovascular disease                | 1,658 (8.3)          |                |
| 4                            | Osteoarthritis                  | 1,832 (6.2)          |  | Cerebrovascular disease                | 1,080 (8.1)          |                | COPD                                   | 1,502 (7.5)          |                |
| 5                            | COPD                            | 1,419 (4.8)          |  | Osteoarthritis                         | 979 (7.4)            |                | Lower respiratory infections           | 1,011 (5.0)          |                |
| 6                            | Unipolar major depression       | 1,384 (4.7)          |  | Alzheimer dementia and other dementias | 959 (7.2)            |                | Genitourinary diseases                 | 996 (5.0)            |                |
| 7                            | Diabetes mellitus               | 1,145 (9.3)          |  | Genitourinary diseases                 | 409 (3.1)            |                | Osteoarthritis                         | 873 (4.4)            |                |
| 8                            | Breast cancer                   | 913 (3.1)            |  | Colon and rectum cancer                | 360 (2.7)            |                | Trachea/bronchus/lung cancer           | 744 (3.7)            |                |
| 9                            | Cirrhosis of the liver          | 812 (2.8)            |  | Diabetes mellitus                      | 339 (2.5)            |                | Falls                                  | 484 (2.4)            |                |
| 10                           | Nutritional/endocrine disorders | 710 (2.4)            |  | Nutritional/endocrine disorders        | 315 (2.4)            |                | Nutritional/endocrine disorders        | 444 (2.2)            |                |
| Total from the top 10 causes |                                 | 16,951 (57.7)        |  |                                        |                      | 9,068 (68.2)   |                                        |                      | 15,202 (75.9)  |
| Total from the 90 causes     |                                 | 29,401 (100.0)       |  |                                        |                      | 13,305 (100.0) |                                        |                      | 20,019 (100.0) |

<sup>a</sup>As small numbers are not reliable or stable, we excluded any disease or injury category with a DALYs <100, resulting in four categories for those aged 0–4 years and four categories for those aged 5–14 years.

DALYs = disability-adjusted life years

COPD = chronic obstructive pulmonary disease

NC = not calculable

HIV/AIDS = human immunodeficiency virus/acquired immunodeficiency syndrome

**Figure 2. Ten leading causes of DALYs for Rhode Island (2008), the U.S. (1996), and Los Angeles County, California (1997)**

| Rank | Rhode Island, 2008                     | U.S., 1996 <sup>a</sup>      | Los Angeles County, 1997 <sup>b</sup> |
|------|----------------------------------------|------------------------------|---------------------------------------|
| 1    | Ischemic heart disease                 | Ischemic heart disease       | Ischemic heart disease                |
| 2    | Unipolar major depression              | Cerebrovascular disease      | Alcohol use                           |
| 3    | Cerebrovascular disease                | Road traffic accidents       | Homicide/violence                     |
| 4    | Alzheimer dementia and other dementias | Unipolar major depression    | Depression                            |
| 5    | Trachea/bronchus/lung cancer           | Trachea/bronchus/lung cancer | Diabetes mellitus                     |
| 6    | COPD                                   | COPD                         | Osteoarthritis                        |
| 7    | Osteoarthritis                         | Alcohol use                  | Cerebrovascular disease               |
| 8    | Drug use                               | Human immunodeficiency virus | Trachea/bronchus/lung cancer          |
| 9    | Road traffic accidents                 | Diabetes mellitus            | COPD                                  |
| 10   | Diabetes mellitus                      | Osteoarthritis               | Road traffic accidents                |

<sup>a</sup>Michaud CM, McKenna MT, Begg S, Tomijima N, Majmudar M, Bulzacchelli MT, et al. The burden of disease and injury in the United States, 1996. *Popul Health Metr* 2006;4:11.

<sup>b</sup>Kominski GF, Simon PA, Ho A, Luck J, Lim YW, Fielding JE. Assessing the burden of disease and injury in Los Angeles County using disability-adjusted life years. *Public Health Rep* 2002;117:185-91.

DALYs = disability-adjusted life years

COPD = chronic obstructive pulmonary disease

than men to develop depression and depression-related disorders during their lifetime, according to several studies.<sup>18,19</sup>

Smoking has been estimated to cause one-third of all cancer deaths in many Western countries and to be responsible for about 11% of all deaths due to cardiovascular disease.<sup>20</sup> Because lung cancer and IHD were both leading causes of DALYs, tobacco use could be considered a significant contributor to RI's overall disease burden.

Osteoarthritis was the seventh leading cause of DALYs in RI, the 10th leading cause of DALYs in the U.S., and the sixth leading cause of DALYs in LA County (Figure 2).<sup>2,3</sup> Osteoarthritis is an important public health problem affecting mostly older adults and is one of the most rapidly growing causes of disability.<sup>6</sup> Researchers have estimated that the 40 million prevalent cases in the U.S. in 1996 will increase 150%—to 60 million cases—by 2020.<sup>2</sup>

Comparison of the causes and rank orders of DALYs, deaths, YLLs, and YLDs, overall and by gender and age, highlights the way nonfatal but disabling chronic and mental health conditions compromise quality of life, and indicates the significant impact of behavioral and mental health conditions on teens and young adults, of asthma on children, and of disparities by gender.

The relative contribution of premature death vs. disability to the estimation of DALYs becomes evident when the causes and rank order of deaths, YLLs, and YLDs are compared with one another. For example, IHD, the number one cause of DALYs, deaths, and

YLLs, did not appear in the top 10 causes of YLDs. Conversely, depression and osteoarthritis, both leading causes of DALYs, were not leading causes of death or of YLLs but were the two leading causes of YLDs.

### Limitations

Estimating DALYs adds a new dimension to assessing the health of RI's population. However, some limitations need to be noted. For one, DALYs calculations require detailed epidemiologic information for many different conditions. Incidence data for most conditions are lacking at the state level, and the use of U.S. incidence estimates may not accurately represent RI's population. Second, we could not assess racial/ethnic disparities in RI because we did not have enough cases to calculate the YLLs by race/ethnicity. Third, numerous decisions and assumptions were made during the calculation process,<sup>1</sup> and these assumptions introduced some uncertainty into the calculations that requires caution when interpreting rankings for causes with small differences in the number of DALYs.

Fourth, the DALY method itself has some limitations. A critique by Grosse et al. notes that disability weights are assigned based on experts' judgments and clinical experience, and by people without disabilities whose judgments are likely to reflect their perception of the undesirability of a disabling condition. These disability weights also did not consider patients' medical treatment, disease stages, and complications. Further, Grosse et al. argue that in the future, DALYs and YLDs estimates should be based on measures of



activity limitations rather than perceived desirability. They also raised an ethics issue, as these weights imply that one year of living in good health is more valuable than living two years in poor health.<sup>21</sup> These criticisms are legitimate and we support refinement of the disability weights that are currently being used in DALYs calculations. However, we believe that the existing disability weights, although imperfect, provide value in enabling the calculation of DALYs, and that DALYs add a much needed dimension to the estimation of disease burden in a population.

Finally, the influence of age weighting on the ranking of conditions is small and has been criticized by some researchers.<sup>3,22</sup> While the use of a discounting rate remains controversial,<sup>7</sup> a comparison study found that the discounting rate made little difference in the end results.<sup>3,5</sup>

Despite these data and methodologic limitations, DALYs, reflecting years of healthy life lost, provide a useful tool for identifying conditions that exact large health burdens in RI's population, as well as for identifying health disparities among age and gender subgroups.

## CONCLUSIONS

This study demonstrates the feasibility of using DALYs to assess the burden of disease and injury at the state level. Assessment of RI DALYs for age and gender subgroups indicated disparities in the causes and significance of conditions, indicating the need for targeted interventions. For example, alcohol and drug use are of particular concern for males, depression and asthma are concerning for females, mental disorders and injuries are concerning for younger adults, road traffic accidents and asthma are a concern for children and young adults, and congenital and perinatal conditions primarily affect infants. Using DALYs to assess the burden of disease and injury at the state or local level can help state and local government decision makers set public health priorities and allocate health resources.<sup>23</sup>

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# Integration of Syndromic Surveillance Data into Public Health Practice at State and Local Levels in North Carolina

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## ABSTRACT

**Objectives.** We sought to describe the integration of syndromic surveillance data into daily surveillance practice at local health departments (LHDs) and make recommendations for the effective integration of syndromic and reportable disease data for public health use.

**Methods.** Structured interviews were conducted with local health directors and communicable disease nursing staff from a stratified random sample of LHDs from May through September 2009. Interviews captured information on direct access to the North Carolina syndromic surveillance system and on the use of syndromic surveillance information for outbreak management, program management, and the creation of reports. We analyzed syndromic surveillance system data to assess the number of signals resulting in a public health response.

**Results.** Syndromic surveillance data were used for outbreak investigation (19% of respondents) and program management and report writing (43% of respondents); a minority reported use of both syndromic and reportable disease data for these purposes (15% and 23%, respectively). Receiving data from frequent system users was associated with using data for these purposes ( $p=0.016$  and  $p=0.033$ , respectively, for syndromic and reportable disease data). A small proportion of signals (<25%) resulted in a public health response.

**Conclusions.** Use of syndromic surveillance data by North Carolina local public health authorities resulted in meaningful public health action, including both case investigation and program management. While useful, the syndromic surveillance data system was oriented toward sensitivity rather than efficiency. Successful incorporation of new surveillance data is likely to require systems that are oriented toward efficiency.

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Effective use of surveillance data is essential to good public health practice. In recent years, public health agencies have experienced a significant increase in the amount of data available for surveillance (e.g., data used for syndromic surveillance), and this increase is likely to continue. For example, the federal Health Information Technology for Economic and Clinical Health Act (HITECH Act) supports forwarding medical record data to public health agencies. Published work demonstrates that better data are needed for communicable disease surveillance; communicable disease reporting is not complete,<sup>1</sup> and many cases are reported later than is necessary for public health action.<sup>2</sup> While the medical record data that may be provided to public health have the potential to improve completeness and timeliness, these datasets are likely to have many records that are not usable for public health purposes.<sup>3</sup> Furthermore, limited staff are available to review these data.<sup>4,5</sup> Effective use of these new data for public health surveillance will require efficient identification of and access to the usable data elements present in new datasets.

The implementation of syndromic surveillance is an example of the incorporation of new data sources. Syndromic surveillance systems were established to facilitate early detection of events requiring a rapid response, such as outbreaks caused by bioterrorism agents. Events that may require public health intervention are identified using aberration detection algorithms and individual record review. Most states have a system of this type,<sup>6</sup> and their value for public health event detection and characterization has been demonstrated.<sup>6-10</sup> Lessons learned from attempts to integrate syndromic data for public health surveillance and response can inform future management of new data.

While syndromic surveillance data can be valuable to public health practice, the design of these systems frequently limits their use to jurisdictions with greater capacity. Alerts created by system algorithms are often of low positive predictive value,<sup>11,12</sup> and these systems can require a high level of staff time for detecting events that require public health action.<sup>8</sup> Therefore, syndromic surveillance data are most commonly used by state and large city public health departments that have enough staff time for reviewing alerts and individual case records.<sup>6,13,14</sup> Although these data can be useful to health departments of all sizes, little is known about how best to make these data usable in situations with limited surveillance staff. The use of syndromic surveillance data in smaller population settings, such as most local health departments (LHDs), has not been described.

North Carolina can provide an example of the integration of syndromic surveillance data into public health surveillance practice. Current electronic surveillance for communicable disease in the state includes a population-based syndromic surveillance system, the North Carolina Disease Event Tracking and Epidemiologic Collection Tool (NC DETECT), and a population-based reportable communicable disease surveillance system, the North Carolina Electronic Disease Surveillance System (NC EDSS). Both syndromic and reportable disease data have been used for public health surveillance since 2006. NC DETECT use is the responsibility of syndromic surveillance staff, which includes two state-level epidemiologists and 11 hospital-based epidemiologists. All other public health agency staff may use NC DETECT. NC EDSS use is required for and restricted to staff responsible for communicable disease reporting at state and local levels.

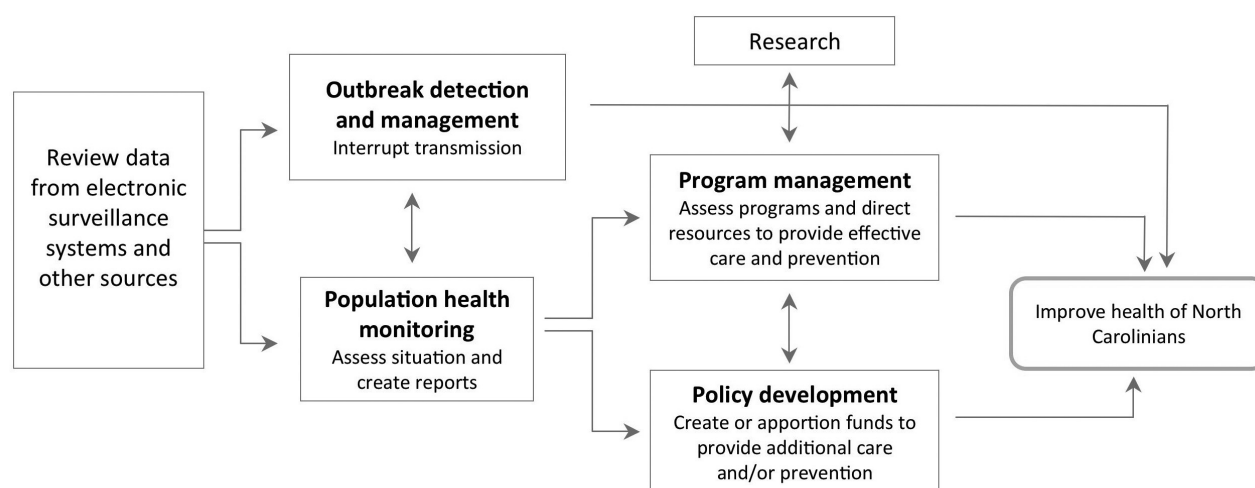
The objectives of this study were to quantitatively assess the use of syndromic surveillance data at state and local public health agencies in North Carolina, to describe how syndromic surveillance is incorporated into public health practice in the state, and to make recommendations for the effective integration of syndromic and reportable disease data for public health use.

## METHODS

Outcome measures for surveillance data use were derived from a logic model of public health surveillance (Figure 1). Measures of syndromic surveillance data use included (1) the proportion of syndromic surveillance signals used for public health action (defined as steps taken by public health staff to investigate or report on population health events); and (2) the proportion of surveillance data users using syndromic surveillance information for outbreak investigation, policy development and program management, and the creation of reports for stakeholders. The measure of combined syndromic and reportable disease data use was the proportion of users reporting use of both syndromic and reportable disease information for these purposes. Published guidelines on surveillance system evaluation were consulted for this assessment.<sup>15-17</sup>

### System data analysis

We examined NC DETECT system data from January to December 2009 to assess the proportion of syndromic surveillance data resulting in public health action. The NC DETECT system captures data from emergency departments (EDs; visit records), the Carolinas Poison Center (CPC; poison control center call records),

**Figure 1. Logic model describing public health surveillance data use in North Carolina**

and the North Carolina Prehospital Medical Information System (PreMIS; emergency medical service run reports). PreMIS data were not used for public health surveillance during the period of this study.

NC DETECT uses algorithm processing to identify dates when the number of cases of a given "syndrome" (a combination of symptoms, such as fever with rash) is higher than comparison data for previous time periods.<sup>18,19</sup> These dates, with the number of syndrome cases and links to the case records, are listed in a database as signals that are reviewable by public health staff. A system variable can be used to record action taken by system users. By default, the variable indicates "not yet documented." After reviewing a signal, syndromic surveillance staff members use this variable to indicate the level of action taken (e.g., active investigation, monitoring, investigation completed, or no action needed). In the rare instances of LHD staff reviewing signals, this variable is generally not used. This action-level variable allows staff to assess the number of signals meriting public health action by syndromic surveillance staff.

We quantified the proportion of signals at each action level, as well as the proportion of signals not reviewed (i.e., signals where the action-level variable still indicated "not yet documented"). We classified signals labeled "active investigation," "monitoring," and "investigation completed" as signals meriting public health action. The types of public health action performed were captured in free-text comments appended to the signal record by syndromic surveillance staff.

### Survey

A survey was conducted from May through September 2009 to gather information on how the NC DETECT system and syndromic surveillance data are used at state and local levels. Information was collected on whether respondents used NC DETECT (direct access) and whether respondents received NC DETECT case records and/or reports from others (indirect access). In addition, information was gathered about two outbreak investigations: a respondent-selected outbreak investigation from the past year (June 2008 to May 2009) and the 2009 H1N1 influenza outbreak (May to August 2009). The survey included questions on how respondents were alerted to events of public health significance, how such events were monitored, and whether NC DETECT and NC EDSS information was used for the outbreak investigations, program management and policy development, and report writing.

The survey population included public health agency staff responsible for surveillance, event response, and program management and policy development. All epidemiologists in the state division of public health communicable disease branch, as well as epidemiologists from other groups with the potential to use data captured by NC DETECT (e.g., an asthma epidemiologist), were invited to participate. The 85 LHDs were stratified by population, and one very large LHD (population >200,000), seven large LHDs (population 53,377–200,000), and seven small LHDs (population <53,377) were randomly selected. The LHD director and a communicable disease nurse



(CD nurse) from each LHD were invited to participate. In all, 48 individuals (18 from state-level health departments and 30 from LHDs) were invited to participate. This sample did not include the hospital-based public health epidemiologists who do not have responsibility for program management and policy development. Two project staff administered the survey via face-to-face interviews and by telephone when face-to-face interviews were not possible.

To examine user characteristics and uses of syndromic surveillance data, proportions were calculated and compared; because of small cell sizes, we used Fisher's exact test and odds ratios (ORs) to assess associations. All quantitative data analysis was performed using SAS® version 9.1.<sup>20</sup> Because responses to questions on program management, policy development, and report writing were similar, we grouped these results for analysis and identified them as program management and report writing. We limited our analysis of the combined use of syndromic and reportable surveillance data to state epidemiologists and local CD nurse staff, who routinely have access to both types of data. (State-level chronic disease, environmental, and injury epidemiologists did not have access to NC EDSS at the time of the survey. In general, LHD directors did not use NC EDSS or NC DETECT.)

## RESULTS

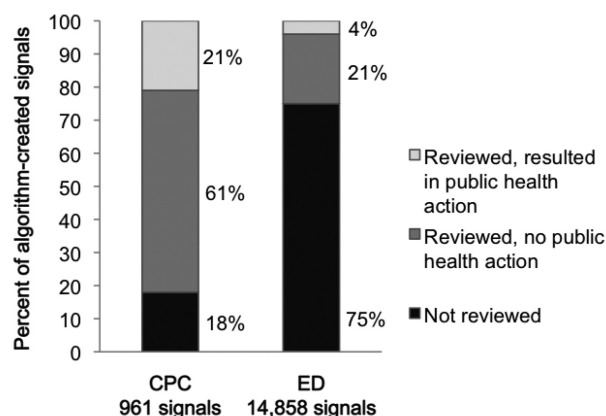
### System data analysis

Between January and December 2009, 961 signals were generated from CPC data and 14,858 signals were generated from ED data. Of the signals from CPC data, 788 (82%) were reviewed, and 199 (21%) resulted in action by public health staff (Figure 2). Of the signals from ED data, 3,715 (25%) were reviewed, and 600 (4%) resulted in action by public health staff. Public health action resulting from signal review included calls to LHDs, other health agencies, and hospitals; participation in investigations; and calls to organizations potentially involved in an outbreak. The majority of ED signals ( $n=11,143$ ; 75%) and a minority of CPC signals ( $n=173$ , 18%) were not reviewed.

### Survey

Forty-four of 48 invitees participated in the survey interview (response rate = 92%). The final survey population included 17 state-level staff (epidemiologists and public health nurses responsible for communicable disease, tuberculosis, immunization, environmental epidemiology, chronic disease, injury, surveillance, and preparedness) and 27 staff from 14 LHDs (14 directors and 13 CD nurses).

**Figure 2. Proportion of NC DETECT signals reviewed and acted upon by public health staff, January–December 2009**



NC DETECT = North Carolina Disease Event Tracking and Epidemiologic Collection Tool

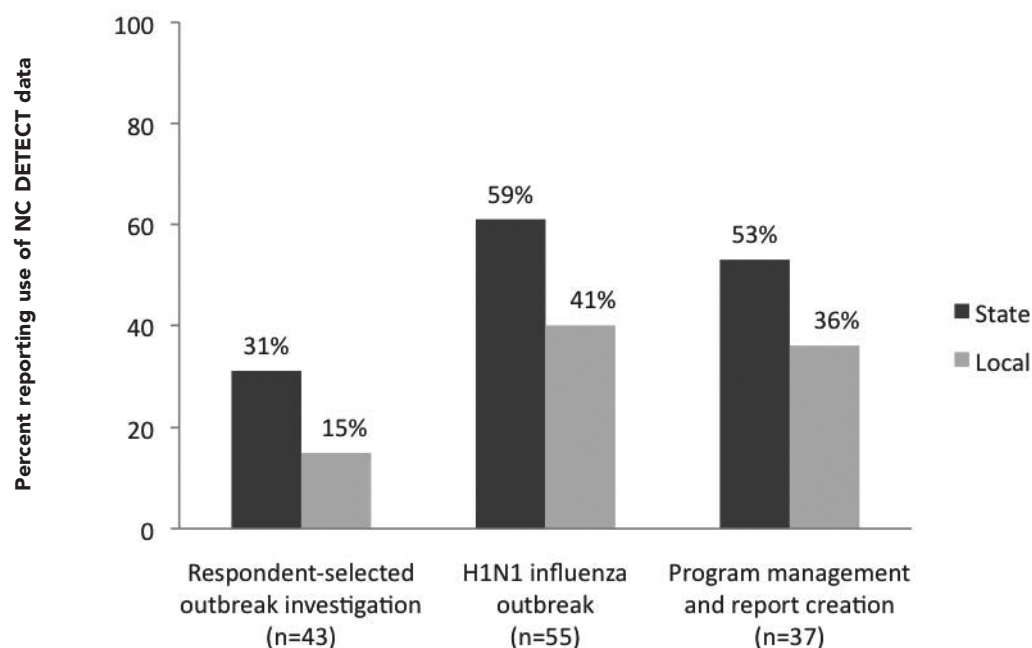
CPC = Carolinas Poison Control

ED = emergency department

Syndromic surveillance data were used for outbreak investigation, program management, and report writing by both state- and local-level public health staff. Among 13 state-level staff participating in an investigation in the past year, 31% (four of 13) reported using NC DETECT data for outbreak investigation (Figure 3). Among LHD staff, 15% (four of 27) reported using these data for outbreak investigation. The proportion of respondents that reported using NC DETECT data for management of the H1N1 influenza outbreak was higher: 59% (10 of 17) among state staff and 41% (11 of 27) among local staff. Among 15 state-level staff participating in program management, eight (53%) reported using NC DETECT data for program management and report writing. Among 22 LHD staff participating in program management, 36% (eight of 22) reported using NC DETECT data for program management and report writing (Figure 3).

Survey respondents reported on their access to NC DETECT in the 12 months preceding the survey. Among the 43 respondents, modes of access included: none ( $n=11$ ), direct only (i.e., respondent used NC DETECT;  $n=5$ ), indirect only (i.e., respondent received information from a user of NC DETECT;  $n=15$ ), or both direct and indirect ( $n=12$ ). Respondents reporting indirect access received case records and/or reports from syndromic surveillance staff (including public health epidemiologists), other state staff, and/or hospital staff. Having indirect access to NC DETECT during the 12 months prior to the survey was associated with

**Figure 3. Proportion of survey respondents using NC DETECT data for public health surveillance activities: North Carolina, June 2008 to June 2009**



NC DETECT = North Carolina Disease Event Tracking and Epidemiologic Collection Tool

use of NC DETECT data during an outbreak (Figure 4;  $p=0.016$ , OR not calculable); respondents without indirect access (whether or not they had direct access) did not report using NC DETECT data for outbreak investigation. Having indirect access to NC DETECT was also associated with the use of syndromic surveillance data for program management and report writing (OR=7.15, 95% confidence interval [CI] 1.3, 39.8). Respondents with both direct and indirect access most frequently reported use of NC DETECT data and information for outbreak investigation, program management, and report writing.

Most state and local communicable disease staff members can create user accounts for both NC DETECT and NC EDSS. Among 13 state-level staff who could use both systems, five (38%) reported having user accounts and using both, while three (23%) LHD CD nurses reported using both (Figure 5). A minority of respondents used data (accessed directly or indirectly) from both systems: four of 26 (15%) staff reported using data from both systems for the respondent-selected outbreak investigation and six of 26 (23%) reported using data from both systems for program management and report writing. However, a higher proportion (14/26; 54%) reported using data from both systems during the H1N1 influenza outbreak (data not shown).

## DISCUSSION

The routine use of syndromic surveillance data by North Carolina state and local public health authorities resulted in meaningful public health action, including both case investigation and program management. Employees at state health departments and LHDs used syndromic surveillance data both for the originally envisioned purpose of syndromic surveillance (early event detection) and for traditional public health practice. Therefore, this new data source has been incorporated into daily surveillance practice in North Carolina and is used for key public health purposes across the state.

Although syndromic surveillance data are used for public health action, the observed association between indirect access and data use suggests that a dedicated staff is required to filter the data to identify events requiring action. This association is addressed at the state level in North Carolina by assigning responsibility for filtering to syndromic surveillance staff. However, because this small staff cannot review all ED data signals, only a subset of signals is reviewed. Because limited staff are available for public health surveillance and epidemiology,<sup>4,5</sup> it is unrealistic to expect this filtering to be performed at the local level. During the H1N1 outbreak, a small number of additional personnel were recruited to send weekly H1N1 influenza

**Figure 4. Use of NC DETECT data for respondent-selected outbreak investigation, program management, and report writing, by access mode: North Carolina, 2009**



<sup>a</sup>Respondent used NC DETECT

<sup>b</sup>Respondent received NC DETECT data or information from a user of NC DETECT

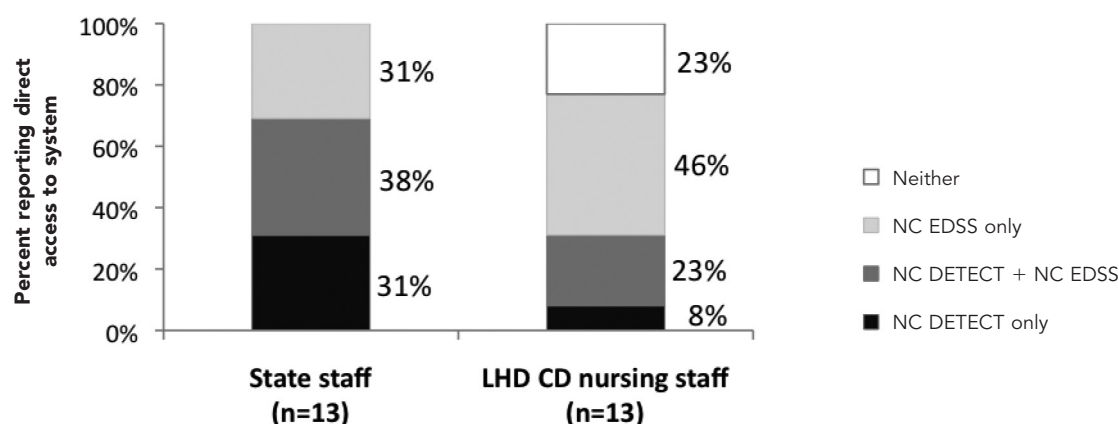
NC DETECT = North Carolina Disease Event Tracking and Epidemiologic Collection Tool

reports including syndromic surveillance information to all LHDs, and reported use of syndromic surveillance information increased. This finding supports the conclusion that the use of syndromic surveillance information is limited by the number of staff available to distribute it.

Although syndromic surveillance information has

been integrated into public health practice at the state level and in some LHDs, the majority of public health staff in North Carolina does not routinely integrate NC DETECT and NC EDSS data for outbreak investigation, program management, or report writing. The syndromic surveillance staff does not have permission to access NC EDSS, so they cannot use NC EDSS data

**Figure 5. Direct access to syndromic and reportable disease surveillance systems among staff members with potential access to both systems (n=26): North Carolina, 2009**



NC EDSS = North Carolina Electronic Disease Surveillance System

NC DETECT = North Carolina Disease Event Tracking and Epidemiologic Collection Tool

LHD = local health department

CD = communicable disease

for context when NC DETECT data are forwarded; and local staff responsible for reportable diseases do not access NC DETECT because it is not structured for their effective use. To have the most complete information on the epidemiology of diseases in North Carolina and the outbreaks affecting the population, public health staff would use data from both NC DETECT and NC EDSS.

### Limitations

Although this study provides novel information on the use of traditional and new communicable disease surveillance systems, it was subject to several important limitations. While syndromic surveillance personnel conduct most signal review, a small number of others review signals but do not use the action-level variable. Therefore, the number of signals with an action-level change captured by the NC DETECT system represents a minimum estimate of the proportion investigated. Information captured on the use of syndromic and reportable disease data for program and report writing purposes was captured only as yes/no. This question could not differentiate between relatively simplistic use of syndromic surveillance data (e.g., inclusion of syndromic surveillance data in one or several reports) and real incorporation of this information into program development and report writing (e.g., ongoing observation of the number of syndrome cases in the jurisdiction EDs and inclusion of these numbers in reports and program planning discussions). Interviews were performed face to face; as such, respondents may have reported using surveillance data systems more frequently than they normally do, resulting in social desirability bias and an overestimation of NC DETECT and NC EDSS use.

### Recommendations

We suggest three strategies to support broader use of syndromic surveillance and other new data. The first is to develop algorithms for syndromic surveillance based on actionability. Our findings and others<sup>8,11,21</sup> show that the proportion of signals requiring public health action is very small. New algorithms could be developed based on the signals that have resulted in public health action historically, with the goal of identifying similar signals. Because these signals are a small proportion of current signals, the total number of signals generated by the modified algorithms should be smaller. A higher proportion of signals created by these new algorithms should merit action by public health staff. The importance of including actionability in creating syndromes is highlighted in work on syndromic surveillance systems across the United

States.<sup>13,18,19</sup> Decreasing the number of non-actionable signals to investigate could decrease the time needed to review syndromic surveillance data.

Second, the group of users directly accessing syndromic surveillance data and reports could be broadened. This broadening could be supported by Web portals designed for users at different levels. Regional and/or local-level portals could be designed, including maps and reports oriented toward local/regional public health action. These reports could include aggregated infectious and/or chronic disease data that are useful for disease reporting, local program management, and report writing; current syndrome signals could also be added if desired. These approaches could also be combined, thereby strengthening syndromic surveillance data algorithms while making the data more accessible via efficient Web portals.

Third, NC DETECT and NC EDSS could be designed to look similar and be accessed by the user from a single website. Currently, the syndromic and reportable disease surveillance systems in North Carolina have a different visual organization and design. The use of similar icons would facilitate moving from one system to the other; graphs and charts could be labeled similarly. The systems could be designed to exchange data electronically; for example, when a pertussis outbreak event is created in NC EDSS, data on the number of cases presenting to the ED with signs and symptoms characteristic of pertussis could be provided in a pop-up box. Design similarity and interoperability could support more effective surveillance data integration.

### CONCLUSIONS

Research has demonstrated that syndromic surveillance data are valuable to national public health practice. Syndromic surveillance systems hold large amounts of data that can go unused, and this is also a potential issue with new types of data. Unless budgets for surveillance are significantly increased, developing computer systems that facilitate the management of these growing data pools will be essential. The focus must be on making review and use of new data efficient, rather than on system sensitivity for rare events. Technology should be used to support public health surveillance practice, providing usable data while allowing increased sensitivity if desired. Future research should include the development of syndromes based on data on public health actionability, and organizational protocols should be developed to support state and local access to important surveillance data.

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## ABSTRACT

**Objectives.** We sought to describe the integration of syndromic surveillance data into daily surveillance practice at local health departments (LHDs) and make recommendations for the effective integration of syndromic and reportable disease data for public health use.

**Methods.** Structured interviews were conducted with local health directors and communicable disease nursing staff from a stratified random sample of LHDs from May through September 2009. Interviews captured information on direct access to the North Carolina syndromic surveillance system and on the use of syndromic surveillance information for outbreak management, program management, and the creation of reports. We analyzed syndromic surveillance system data to assess the number of signals resulting in a public health response.

**Results.** Syndromic surveillance data were used for outbreak investigation (19% of respondents) and program management and report writing (43% of respondents); a minority reported use of both syndromic and reportable disease data for these purposes (15% and 23%, respectively). Receiving data from frequent system users was associated with using data for these purposes ( $p=0.016$  and  $p=0.033$ , respectively, for syndromic and reportable disease data). A small proportion of signals (<25%) resulted in a public health response.

**Conclusions.** Use of syndromic surveillance data by North Carolina local public health authorities resulted in meaningful public health action, including both case investigation and program management. While useful, the syndromic surveillance data system was oriented toward sensitivity rather than efficiency. Successful incorporation of new surveillance data is likely to require systems that are oriented toward efficiency.

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Effective use of surveillance data is essential to good public health practice. In recent years, public health agencies have experienced a significant increase in the amount of data available for surveillance (e.g., data used for syndromic surveillance), and this increase is likely to continue. For example, the federal Health Information Technology for Economic and Clinical Health Act (HITECH Act) supports forwarding medical record data to public health agencies. Published work demonstrates that better data are needed for communicable disease surveillance; communicable disease reporting is not complete,<sup>1</sup> and many cases are reported later than is necessary for public health action.<sup>2</sup> While the medical record data that may be provided to public health have the potential to improve completeness and timeliness, these datasets are likely to have many records that are not usable for public health purposes.<sup>3</sup> Furthermore, limited staff are available to review these data.<sup>4,5</sup> Effective use of these new data for public health surveillance will require efficient identification of and access to the usable data elements present in new datasets.

The implementation of syndromic surveillance is an example of the incorporation of new data sources. Syndromic surveillance systems were established to facilitate early detection of events requiring a rapid response, such as outbreaks caused by bioterrorism agents. Events that may require public health intervention are identified using aberration detection algorithms and individual record review. Most states have a system of this type,<sup>6</sup> and their value for public health event detection and characterization has been demonstrated.<sup>6-10</sup> Lessons learned from attempts to integrate syndromic data for public health surveillance and response can inform future management of new data.

While syndromic surveillance data can be valuable to public health practice, the design of these systems frequently limits their use to jurisdictions with greater capacity. Alerts created by system algorithms are often of low positive predictive value,<sup>11,12</sup> and these systems can require a high level of staff time for detecting events that require public health action.<sup>8</sup> Therefore, syndromic surveillance data are most commonly used by state and large city public health departments that have enough staff time for reviewing alerts and individual case records.<sup>6,13,14</sup> Although these data can be useful to health departments of all sizes, little is known about how best to make these data usable in situations with limited surveillance staff. The use of syndromic surveillance data in smaller population settings, such as most local health departments (LHDs), has not been described.

North Carolina can provide an example of the integration of syndromic surveillance data into public health surveillance practice. Current electronic surveillance for communicable disease in the state includes a population-based syndromic surveillance system, the North Carolina Disease Event Tracking and Epidemiologic Collection Tool (NC DETECT), and a population-based reportable communicable disease surveillance system, the North Carolina Electronic Disease Surveillance System (NC EDSS). Both syndromic and reportable disease data have been used for public health surveillance since 2006. NC DETECT use is the responsibility of syndromic surveillance staff, which includes two state-level epidemiologists and 11 hospital-based epidemiologists. All other public health agency staff may use NC DETECT. NC EDSS use is required for and restricted to staff responsible for communicable disease reporting at state and local levels.

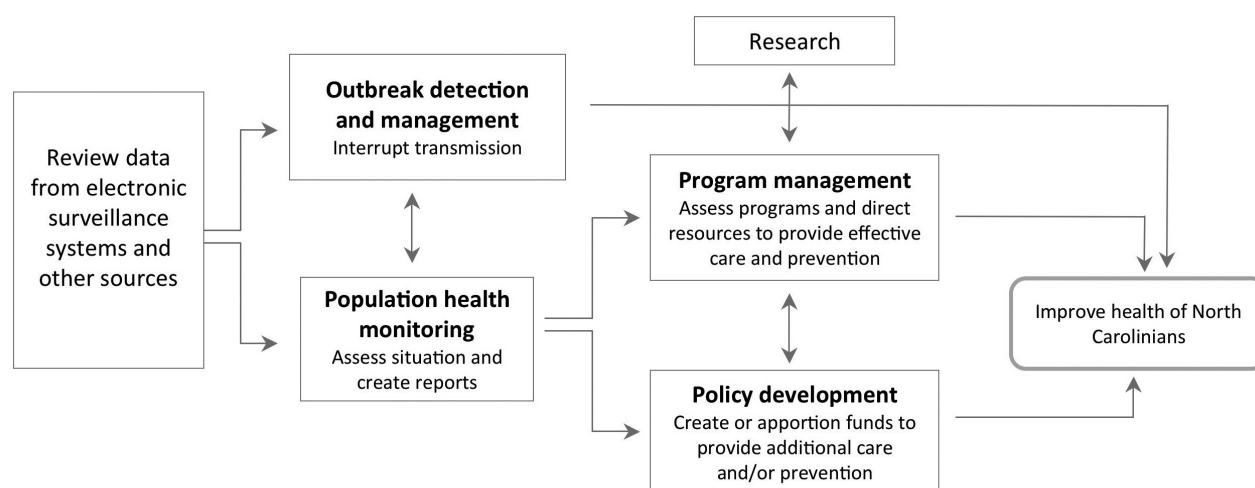
The objectives of this study were to quantitatively assess the use of syndromic surveillance data at state and local public health agencies in North Carolina, to describe how syndromic surveillance is incorporated into public health practice in the state, and to make recommendations for the effective integration of syndromic and reportable disease data for public health use.

## METHODS

Outcome measures for surveillance data use were derived from a logic model of public health surveillance (Figure 1). Measures of syndromic surveillance data use included (1) the proportion of syndromic surveillance signals used for public health action (defined as steps taken by public health staff to investigate or report on population health events); and (2) the proportion of surveillance data users using syndromic surveillance information for outbreak investigation, policy development and program management, and the creation of reports for stakeholders. The measure of combined syndromic and reportable disease data use was the proportion of users reporting use of both syndromic and reportable disease information for these purposes. Published guidelines on surveillance system evaluation were consulted for this assessment.<sup>15-17</sup>

### System data analysis

We examined NC DETECT system data from January to December 2009 to assess the proportion of syndromic surveillance data resulting in public health action. The NC DETECT system captures data from emergency departments (EDs; visit records), the Carolinas Poison Center (CPC; poison control center call records),

**Figure 1. Logic model describing public health surveillance data use in North Carolina**

and the North Carolina Prehospital Medical Information System (PreMIS; emergency medical service run reports). PreMIS data were not used for public health surveillance during the period of this study.

NC DETECT uses algorithm processing to identify dates when the number of cases of a given “syndrome” (a combination of symptoms, such as fever with rash) is higher than comparison data for previous time periods.<sup>18,19</sup> These dates, with the number of syndrome cases and links to the case records, are listed in a database as signals that are reviewable by public health staff. A system variable can be used to record action taken by system users. By default, the variable indicates “not yet documented.” After reviewing a signal, syndromic surveillance staff members use this variable to indicate the level of action taken (e.g., active investigation, monitoring, investigation completed, or no action needed). In the rare instances of LHD staff reviewing signals, this variable is generally not used. This action-level variable allows staff to assess the number of signals meriting public health action by syndromic surveillance staff.

We quantified the proportion of signals at each action level, as well as the proportion of signals not reviewed (i.e., signals where the action-level variable still indicated “not yet documented”). We classified signals labeled “active investigation,” “monitoring,” and “investigation completed” as signals meriting public health action. The types of public health action performed were captured in free-text comments appended to the signal record by syndromic surveillance staff.

### Survey

A survey was conducted from May through September 2009 to gather information on how the NC DETECT system and syndromic surveillance data are used at state and local levels. Information was collected on whether respondents used NC DETECT (direct access) and whether respondents received NC DETECT case records and/or reports from others (indirect access). In addition, information was gathered about two outbreak investigations: a respondent-selected outbreak investigation from the past year (June 2008 to May 2009) and the 2009 H1N1 influenza outbreak (May to August 2009). The survey included questions on how respondents were alerted to events of public health significance, how such events were monitored, and whether NC DETECT and NC EDSS information was used for the outbreak investigations, program management and policy development, and report writing.

The survey population included public health agency staff responsible for surveillance, event response, and program management and policy development. All epidemiologists in the state division of public health communicable disease branch, as well as epidemiologists from other groups with the potential to use data captured by NC DETECT (e.g., an asthma epidemiologist), were invited to participate. The 85 LHDs were stratified by population, and one very large LHD (population >200,000), seven large LHDs (population 53,377–200,000), and seven small LHDs (population <53,377) were randomly selected. The LHD director and a communicable disease nurse

(CD nurse) from each LHD were invited to participate. In all, 48 individuals (18 from state-level health departments and 30 from LHDs) were invited to participate. This sample did not include the hospital-based public health epidemiologists who do not have responsibility for program management and policy development. Two project staff administered the survey via face-to-face interviews and by telephone when face-to-face interviews were not possible.

To examine user characteristics and uses of syndromic surveillance data, proportions were calculated and compared; because of small cell sizes, we used Fisher's exact test and odds ratios (ORs) to assess associations. All quantitative data analysis was performed using SAS® version 9.1.<sup>20</sup> Because responses to questions on program management, policy development, and report writing were similar, we grouped these results for analysis and identified them as program management and report writing. We limited our analysis of the combined use of syndromic and reportable surveillance data to state epidemiologists and local CD nurse staff, who routinely have access to both types of data. (State-level chronic disease, environmental, and injury epidemiologists did not have access to NC EDSS at the time of the survey. In general, LHD directors did not use NC EDSS or NC DETECT.)

## RESULTS

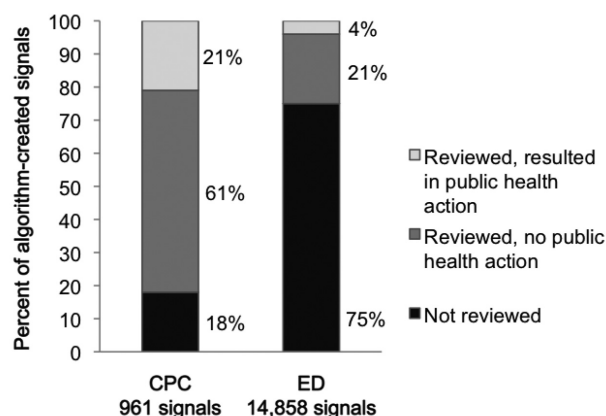
### System data analysis

Between January and December 2009, 961 signals were generated from CPC data and 14,858 signals were generated from ED data. Of the signals from CPC data, 788 (82%) were reviewed, and 199 (21%) resulted in action by public health staff (Figure 2). Of the signals from ED data, 3,715 (25%) were reviewed, and 600 (4%) resulted in action by public health staff. Public health action resulting from signal review included calls to LHDs, other health agencies, and hospitals; participation in investigations; and calls to organizations potentially involved in an outbreak. The majority of ED signals ( $n=11,143$ ; 75%) and a minority of CPC signals ( $n=173$ , 18%) were not reviewed.

### Survey

Forty-four of 48 invitees participated in the survey interview (response rate = 92%). The final survey population included 17 state-level staff (epidemiologists and public health nurses responsible for communicable disease, tuberculosis, immunization, environmental epidemiology, chronic disease, injury, surveillance, and preparedness) and 27 staff from 14 LHDs (14 directors and 13 CD nurses).

**Figure 2. Proportion of NC DETECT signals reviewed and acted upon by public health staff, January–December 2009**



NC DETECT = North Carolina Disease Event Tracking and Epidemiologic Collection Tool

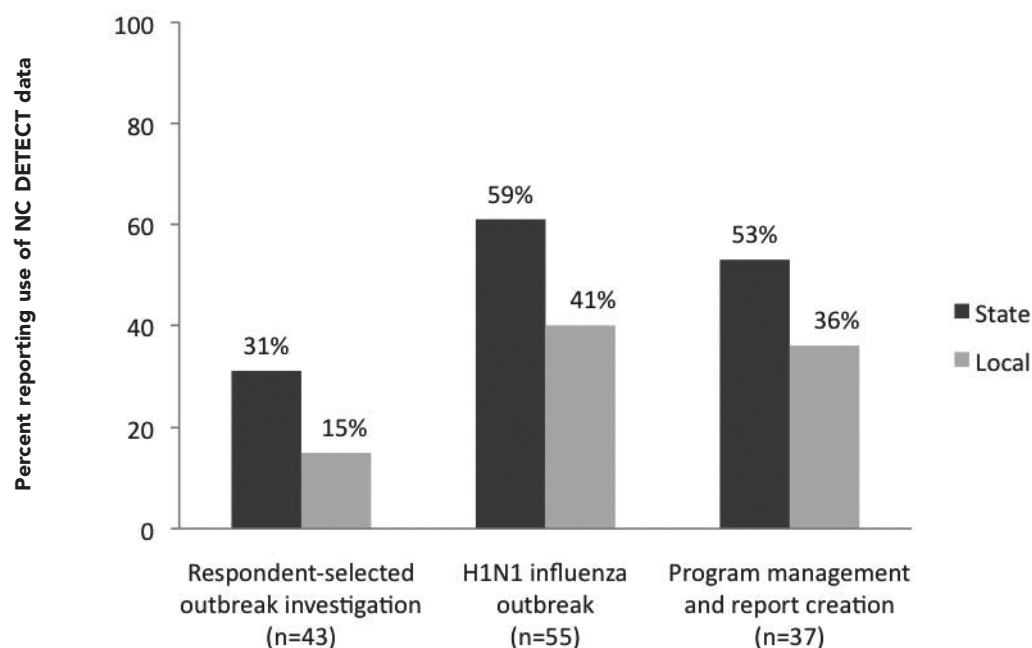
CPC = Carolinas Poison Control

ED = emergency department

Syndromic surveillance data were used for outbreak investigation, program management, and report writing by both state- and local-level public health staff. Among 13 state-level staff participating in an investigation in the past year, 31% (four of 13) reported using NC DETECT data for outbreak investigation (Figure 3). Among LHD staff, 15% (four of 27) reported using these data for outbreak investigation. The proportion of respondents that reported using NC DETECT data for management of the H1N1 influenza outbreak was higher: 59% (10 of 17) among state staff and 41% (11 of 27) among local staff. Among 15 state-level staff participating in program management, eight (53%) reported using NC DETECT data for program management and report writing. Among 22 LHD staff participating in program management, 36% (eight of 22) reported using NC DETECT data for program management and report writing (Figure 3).

Survey respondents reported on their access to NC DETECT in the 12 months preceding the survey. Among the 43 respondents, modes of access included: none ( $n=11$ ), direct only (i.e., respondent used NC DETECT;  $n=5$ ), indirect only (i.e., respondent received information from a user of NC DETECT;  $n=15$ ), or both direct and indirect ( $n=12$ ). Respondents reporting indirect access received case records and/or reports from syndromic surveillance staff (including public health epidemiologists), other state staff, and/or hospital staff. Having indirect access to NC DETECT during the 12 months prior to the survey was associated with

**Figure 3. Proportion of survey respondents using NC DETECT data for public health surveillance activities: North Carolina, June 2008 to June 2009**



NC DETECT = North Carolina Disease Event Tracking and Epidemiologic Collection Tool

use of NC DETECT data during an outbreak (Figure 4;  $p=0.016$ , OR not calculable); respondents without indirect access (whether or not they had direct access) did not report using NC DETECT data for outbreak investigation. Having indirect access to NC DETECT was also associated with the use of syndromic surveillance data for program management and report writing (OR=7.15, 95% confidence interval [CI] 1.3, 39.8). Respondents with both direct and indirect access most frequently reported use of NC DETECT data and information for outbreak investigation, program management, and report writing.

Most state and local communicable disease staff members can create user accounts for both NC DETECT and NC EDSS. Among 13 state-level staff who could use both systems, five (38%) reported having user accounts and using both, while three (23%) LHD CD nurses reported using both (Figure 5). A minority of respondents used data (accessed directly or indirectly) from both systems: four of 26 (15%) staff reported using data from both systems for the respondent-selected outbreak investigation and six of 26 (23%) reported using data from both systems for program management and report writing. However, a higher proportion (14/26; 54%) reported using data from both systems during the H1N1 influenza outbreak (data not shown).

## DISCUSSION

The routine use of syndromic surveillance data by North Carolina state and local public health authorities resulted in meaningful public health action, including both case investigation and program management. Employees at state health departments and LHDs used syndromic surveillance data both for the originally envisioned purpose of syndromic surveillance (early event detection) and for traditional public health practice. Therefore, this new data source has been incorporated into daily surveillance practice in North Carolina and is used for key public health purposes across the state.

Although syndromic surveillance data are used for public health action, the observed association between indirect access and data use suggests that a dedicated staff is required to filter the data to identify events requiring action. This association is addressed at the state level in North Carolina by assigning responsibility for filtering to syndromic surveillance staff. However, because this small staff cannot review all ED data signals, only a subset of signals is reviewed. Because limited staff are available for public health surveillance and epidemiology,<sup>4,5</sup> it is unrealistic to expect this filtering to be performed at the local level. During the H1N1 outbreak, a small number of additional personnel were recruited to send weekly H1N1 influenza



**Figure 4. Use of NC DETECT data for respondent-selected outbreak investigation, program management, and report writing, by access mode: North Carolina, 2009**



<sup>a</sup>Respondent used NC DETECT

<sup>b</sup>Respondent received NC DETECT data or information from a user of NC DETECT

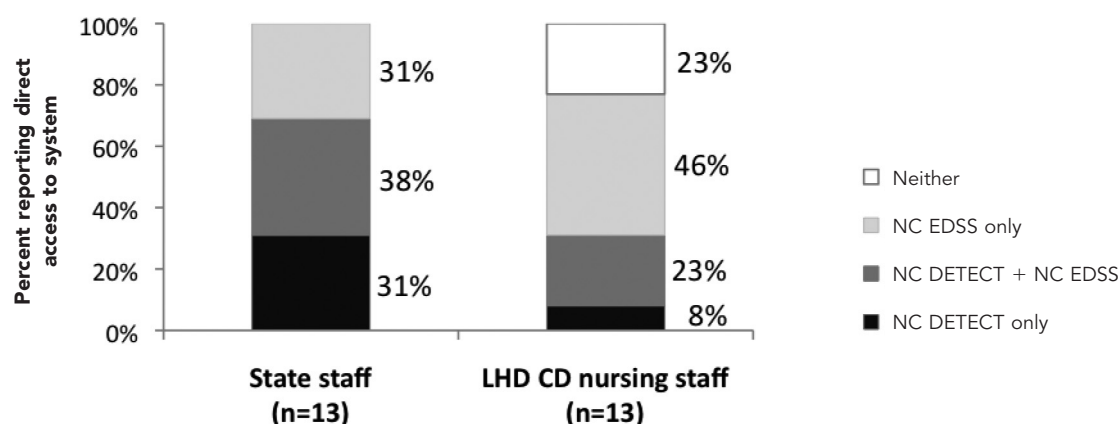
NC DETECT = North Carolina Disease Event Tracking and Epidemiologic Collection Tool

reports including syndromic surveillance information to all LHDs, and reported use of syndromic surveillance information increased. This finding supports the conclusion that the use of syndromic surveillance information is limited by the number of staff available to distribute it.

Although syndromic surveillance information has

been integrated into public health practice at the state level and in some LHDs, the majority of public health staff in North Carolina does not routinely integrate NC DETECT and NC EDSS data for outbreak investigation, program management, or report writing. The syndromic surveillance staff does not have permission to access NC EDSS, so they cannot use NC EDSS data

**Figure 5. Direct access to syndromic and reportable disease surveillance systems among staff members with potential access to both systems (n=26): North Carolina, 2009**



NC EDSS = North Carolina Electronic Disease Surveillance System

NC DETECT = North Carolina Disease Event Tracking and Epidemiologic Collection Tool

LHD = local health department

CD = communicable disease

for context when NC DETECT data are forwarded; and local staff responsible for reportable diseases do not access NC DETECT because it is not structured for their effective use. To have the most complete information on the epidemiology of diseases in North Carolina and the outbreaks affecting the population, public health staff would use data from both NC DETECT and NC EDSS.

### Limitations

Although this study provides novel information on the use of traditional and new communicable disease surveillance systems, it was subject to several important limitations. While syndromic surveillance personnel conduct most signal review, a small number of others review signals but do not use the action-level variable. Therefore, the number of signals with an action-level change captured by the NC DETECT system represents a minimum estimate of the proportion investigated. Information captured on the use of syndromic and reportable disease data for program and report writing purposes was captured only as yes/no. This question could not differentiate between relatively simplistic use of syndromic surveillance data (e.g., inclusion of syndromic surveillance data in one or several reports) and real incorporation of this information into program development and report writing (e.g., ongoing observation of the number of syndrome cases in the jurisdiction EDs and inclusion of these numbers in reports and program planning discussions). Interviews were performed face to face; as such, respondents may have reported using surveillance data systems more frequently than they normally do, resulting in social desirability bias and an overestimation of NC DETECT and NC EDSS use.

### Recommendations

We suggest three strategies to support broader use of syndromic surveillance and other new data. The first is to develop algorithms for syndromic surveillance based on actionability. Our findings and others<sup>8,11,21</sup> show that the proportion of signals requiring public health action is very small. New algorithms could be developed based on the signals that have resulted in public health action historically, with the goal of identifying similar signals. Because these signals are a small proportion of current signals, the total number of signals generated by the modified algorithms should be smaller. A higher proportion of signals created by these new algorithms should merit action by public health staff. The importance of including actionability in creating syndromes is highlighted in work on syndromic surveillance systems across the United

States.<sup>13,18,19</sup> Decreasing the number of non-actionable signals to investigate could decrease the time needed to review syndromic surveillance data.

Second, the group of users directly accessing syndromic surveillance data and reports could be broadened. This broadening could be supported by Web portals designed for users at different levels. Regional and/or local-level portals could be designed, including maps and reports oriented toward local/regional public health action. These reports could include aggregated infectious and/or chronic disease data that are useful for disease reporting, local program management, and report writing; current syndrome signals could also be added if desired. These approaches could also be combined, thereby strengthening syndromic surveillance data algorithms while making the data more accessible via efficient Web portals.

Third, NC DETECT and NC EDSS could be designed to look similar and be accessed by the user from a single website. Currently, the syndromic and reportable disease surveillance systems in North Carolina have a different visual organization and design. The use of similar icons would facilitate moving from one system to the other; graphs and charts could be labeled similarly. The systems could be designed to exchange data electronically; for example, when a pertussis outbreak event is created in NC EDSS, data on the number of cases presenting to the ED with signs and symptoms characteristic of pertussis could be provided in a pop-up box. Design similarity and interoperability could support more effective surveillance data integration.

### CONCLUSIONS

Research has demonstrated that syndromic surveillance data are valuable to national public health practice. Syndromic surveillance systems hold large amounts of data that can go unused, and this is also a potential issue with new types of data. Unless budgets for surveillance are significantly increased, developing computer systems that facilitate the management of these growing data pools will be essential. The focus must be on making review and use of new data efficient, rather than on system sensitivity for rare events. Technology should be used to support public health surveillance practice, providing usable data while allowing increased sensitivity if desired. Future research should include the development of syndromes based on data on public health actionability, and organizational protocols should be developed to support state and local access to important surveillance data.

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# Patient and Clinician Ethical Perspectives on the 2006 Centers for Disease Control and Prevention HIV Testing Methods

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## ABSTRACT

**Objectives.** CDC 2006 recommendations for new HIV testing methods in U.S. health-care settings (opt-out approach, general medical consent, and optional prevention counseling) have been the subject of a public ethical debate. Ethical concerns might limit their implementation and affect expanded HIV screening efforts. We compared clinicians' and patients' perspectives on the ethical concerns raised about, justifications provided in support of, and preferences for the 2006 CDC-recommended HIV testing methods for the U.S. health-care setting, in contrast with the 2001 CDC-recommended HIV testing methods (opt-in approach, specific written consent, and mandatory prevention counseling).

**Methods.** We conducted a non-inferiority trial and survey of 249 clinicians and random samples of 1,013 of their patients at three emergency departments and three ambulatory care clinics at university-affiliated hospitals in Rhode Island from June to December 2007.

**Results.** Clinicians found the 2006 CDC HIV testing methods to be more ethically concerning than the 2001 testing methods (i.e., ethically inferior), while patients had few ethical concerns. In regard to ethical justifications cited for the 2006 CDC HIV testing methods, clinicians were more supportive of the ethical justifications cited for using an opt-out approach and general medical consent, while patients were more supportive of the justifications for optional HIV prevention counseling. Clinicians showed a relatively greater preference for the opt-out approach and use of general medical consent, while patients had a relatively greater preference for optional HIV prevention counseling.

**Conclusions.** Clinicians and their patients hold divergent ethical perspectives on CDC's 2006 HIV testing methods. The results indicate an opportunity to review not only these but also future HIV testing recommendations, as well as how they are presented for implementation.

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In September 2006, the Centers for Disease Control and Prevention (CDC) released revised recommendations for human immunodeficiency virus (HIV) testing in U.S. clinical settings.<sup>1</sup> The 2006 recommendations, as compared with those from 2001,<sup>2</sup> contained three substantial changes in HIV testing methods, which elicited considerable ethical debate. For these changes, CDC recommended the use of (1) an opt-out instead of an opt-in approach to initiating HIV testing, (2) general medical consent instead of specific signed consent for HIV testing, and (3) optional rather than mandatory prevention counseling at the time of HIV testing. CDC believed that use of these new methods was ethically justified because their implementation would ultimately lead to a reduction in HIV transmission by increasing HIV testing and facilitating linkage to care for those who are HIV infected.<sup>1</sup> However, some leaders in HIV care and advocacy expressed ethical concerns about these new HIV testing methods.<sup>3–15</sup> These concerns included doubts that patients would be duly informed about being tested, might be tested without consent, and might lose opportunities for counseling to reduce their risk of acquiring an HIV infection.

It is unknown to what extent clinicians and their patients agree with the ethical concerns voiced about CDC's 2006 HIV testing methods or believe that their implementation is ultimately morally justified. Concerns about the testing methods and skepticism about the justifications offered in support of them could adversely affect the success of increasing HIV testing in the United States. Furthermore, if patients and clinicians differ in their beliefs about the moral acceptability of the 2006 testing methods, there could be conflicts that might undermine the clinician-patient trust, which could reduce patients' willingness to be tested for HIV. Although minor concerns about the testing methods and differences in perspectives between patients and clinicians might be overcome by education, time, and experience, major concerns and conflicts might indicate the need for further changes in HIV testing methods. Concerns about prior CDC HIV testing recommendations from the early years of the epidemic led to substantial changes in testing methods.<sup>2,16–18</sup> Understanding the moral acceptability of CDC's 2006 recommendations for health-care settings is particularly timely given CDC's plan to release new recommendations for HIV testing in nonclinical settings.<sup>19</sup>

The primary objectives of this study were to investigate if (1) clinicians and their patients believe that the three CDC 2006 HIV testing methods are ethically concerning and (2) the testing methods can accomplish the justifications cited in support of their imple-

mentation. We were particularly interested in finding out if patients and their clinicians found the 2006 HIV testing methods at least as morally acceptable as (i.e., not ethically inferior to) the HIV testing methods CDC previously recommended in 2001. Further, we aimed to determine to what extent clinicians and patients differed on their perspectives about and their preferences for the 2006 vs. 2001 CDC-recommended HIV testing methods.

## METHODS

### Study setting

This study enrolled patients and their clinicians from June to December 2007 at six study sites located within three academic hospitals (Memorial Hospital of Rhode Island, The Miriam Hospital, and Rhode Island Hospital) affiliated with the Alpert Medical School of Brown University. The three hospitals are engaged in teaching programs for medical students, residents, and fellows. The six study sites at the three hospitals were three emergency departments (EDs), two internal medicine clinics, and one family medicine clinic. HIV prevalence in Rhode Island's general population is approximately 0.3%, which is similar to the national average.<sup>20</sup> Our prior research identified an HIV prevalence of <1% among 18- to 64-year-old Rhode Island Hospital ED patients.<sup>21</sup> HIV prevalence at the other study sites has not been estimated.

### Study population

All clinicians (i.e., attending, fellow, and resident physicians; nurse practitioners; and physician assistants) who worked at the EDs and clinics at the six study sites were invited to participate. A random sample of 18- to 64-year-old English- or Spanish-speaking patients at the study sites were assessed for study eligibility, and those who were eligible were invited to participate. Patients were excluded if they were critically ill or injured, inmates or on home confinement, known to be HIV infected, participants in an HIV vaccine study, or unable to provide consent or participate in the study because of an acute psychiatric condition or physical or mental impairment.

For the clinics, we randomly selected dates and times to conduct the study. We approached all patients in the clinic on those random dates and times and assessed their eligibility for the study. For the EDs, we randomly selected dates and times to collect data for the study based upon the typical patterns of patient registration to these EDs, using sampling methods performed in our previous studies.<sup>22,23</sup> Accordingly, 40% of the eight-hour shifts for data collection were from 8 a.m.



to 4 p.m., 50% were from 4 p.m. to 12 a.m., and 10% were from 12 a.m. to 8 a.m. Due to the much larger number of patients available to approach in the ED vs. clinic settings, we also randomly selected patients present in the ED during those shifts to approach for an assessment of their study eligibility and possible enrollment.

### Development of study instruments

We developed the “Ethical Perspectives on the 2006 CDC HIV Testing Recommendations Questionnaire” specifically for this study (available from: URL: [http://www.research.brown.edu/pdf/Ethical\\_Perspectives\\_on\\_the\\_2006\\_CDC\\_HIV\\_Testing\\_Recommendations\\_Questionnaire.doc](http://www.research.brown.edu/pdf/Ethical_Perspectives_on_the_2006_CDC_HIV_Testing_Recommendations_Questionnaire.doc)). The questionnaire was developed by our multidisciplinary research team of emergency medicine, family medicine, internal medicine, and HIV specialist clinicians; a philosopher-bioethicist; a survey methodologist; an epidemiologist; and a biostatistician. From our review of the 2006 CDC recommendations, research conducted, and commentaries published in the lay and medical literature on this topic,<sup>24</sup> we identified recurring ethical concerns about and justifications for the three 2006 HIV testing methods (opt-out approach, general medical consent, and optional prevention counseling). We created the questionnaire based upon these concerns and justifications.

We conducted cognitive-based assessments of the English- and Spanish-language versions of the questionnaire to assess and revise the questions, instructions, and accompanying images in an iterative fashion using techniques recommended by other investigators.<sup>25–28</sup> For these assessments, we enrolled five female and five male attending physicians and residents at a hospital affiliated with our medical school, but not a part of the study, and five English- and five Spanish-speaking 18- to 64-year-old patients at each of the six study sites. We enrolled an equal number of patients based upon age group (18–33, 34–49, and 50–64 years of age), gender, race (white or nonwhite), and years of formal education (<12 years, 12 years, or >12 years). Participants in the cognitive-based assessments received a \$15 gift card to a local pharmacy.

### Study instruments description and instrument administration

The questionnaire consists of three parts that correspond to concerns (Part I), justifications (Part II), and preferences (Part III). For Part I, participants were randomly assigned to view a fictional scenario in which a clinician employed either the 2006 or the 2001 CDC-recommended testing methods for each of the three typical phases of the HIV testing process:

(1) initiating HIV testing (opt-out [2006] vs. opt-in [2001] approach); (2) obtaining consent for HIV testing (general medical [2006] vs. specific signed [2001] consent); and (3) offering prevention counseling (optional [2006] vs. mandatory [2001]). Participants were asked questions about the scenario they viewed. The questions measured the extent to which the participants agreed with the moral concerns raised in the lay and medical literature about the three 2006 CDC testing methods. Participants were randomly assigned to view either a 2006 or a 2001 scenario for each phase of the testing process, so that they would consider each phase of the testing process separately and not believe that the scenarios presented from each phase were linked. Accordingly, because there were two methods to view for three phases, there were eight possible randomization patterns. For purposes of analysis, participants were grouped into two study arms (2006 or 2001 testing method) for each of the three phases. Block randomization was used for the assignments for Part I by study site.

In Part II, participants were shown both the 2006 and 2001 HIV testing method fictional scenarios from Part I simultaneously. They were asked to compare the scenarios in accompanying questions that measured the extent to which they agreed with the ethical justifications for the 2006 CDC testing methods. In Part III, participants again were shown both scenarios from Part I simultaneously and asked to indicate which HIV testing method they preferred for each phase of the HIV testing process. Participants were also asked about their demographic characteristics and HIV testing history using questions developed for previous studies.<sup>23,29</sup> Responses to all questionnaires were anonymous.

The scenarios and questions were purposely designed to enable those without prior knowledge or experience with either the 2006 or the 2001 CDC HIV testing methods to provide their perspectives. Participants viewed the scenarios as if they were an observer and not someone administering or receiving the testing method. They were not informed which scenario represented either the 2006 or the 2001 HIV testing methods, and which methods were currently recommended by CDC. Participants were not informed of any controversy about or justifications for the HIV testing methods being displayed.

Patients completed the study in the waiting and treatment rooms of the ambulatory care clinics and EDs. Patients were administered the questionnaire using an audio computer-assisted self-interviewer (ACASI) system by which they viewed the scenarios and listened to professional audio voice recordings of the study questions and instructions. Patients were not offered an

incentive for participating but were invited to undergo free rapid HIV testing after completing the study. Clinicians received e-mail, mail, and verbal notices and reminders about the study and were given a \$5 gift card to a local store as an incentive for participating. Clinicians who completed the study were entered into a lottery to win a prize worth \$125. Most participants completed the survey within 10–15 minutes.

### Data analysis

Summary statistics (e.g., means, proportions, and 95% confidence intervals [CIs]) were computed for study eligibility assessment, enrollment, and participation, and for responses to the study instruments. Missing responses to the ethical perspectives questionnaire were imputed using the demographic characteristics as predictor variables per recommended multivariable regression techniques.<sup>30</sup> We compared demographic characteristics and HIV testing history of patients vs. clinicians using Wilcoxon signed-rank tests for continuous variables and Pearson's Chi-square tests for categorical variables. Differences at the  $\alpha=0.05$  level were considered significant for all analyses.

For Part I of the study, we examined if participants believed that the 2006 CDC HIV testing methods had the same level of ethical concerns as the 2001 CDC HIV testing methods (i.e., considered the 2006 CDC HIV testing methods to be similar [i.e., not inferior] to the 2001 testing methods in regard to ethical concerns). We used a non-inferiority approach to test whether or not differences in the level of ethical concerns between participants assigned to the two study arms (2006 vs. 2001 testing methods) by testing phase (opt-out vs. opt-in approach, general medical vs. specific signed consent, optional vs. mandatory HIV prevention counseling) were small. For non-inferiority studies, a 10% reduction in the lower limit of the mean of the values measured for the reference study arm (in this case, the 2001 HIV testing methods) is typically used as the criterion for non-inferiority.<sup>31</sup> Accordingly, we established a uniform standard for establishing non-inferiority for each concern evaluated in Part I of the questionnaire. Because the scale measuring the level of concerns in Part I ranged from 0 (no concern) to 4 (high level of concern) points, we established that a <10% difference between study arms (0.4 points) would be the non-inferiority criterion. We calculated the difference in means to the responses to the concerns tested in Part I between study arms, along with corresponding 95% CIs. We estimated a priori that at least 332 participants in each study arm would be required ( $\alpha=0.05$ ,  $\beta=0.01$ ) to determine non-inferiority in Part I, which was the primary aim of the study.

For Part II of the study, we calculated the mean and corresponding 95% CI for each response to the questions about justifications for implementing the 2006 vs. 2001 HIV testing methods. The scale for these responses ranged from –2 (greater support for the 2006 HIV testing methods) to +2 (greater support for the 2001 HIV testing methods). If the 95% CI included zero, then both the 2001 and 2006 HIV testing methods were considered to be equally justified. For Part III of the study, we calculated the mean and corresponding 95% CI for the difference in proportions for those who preferred the 2001 vs. 2006 HIV testing methods.

We performed multivariable logistic regression analyses to compare the magnitude of differences in ethical concerns between clinicians and patients about the 2006 vs. 2001 HIV testing methods. We created similar models to compare the extent to which clinicians and patients supported the moral justifications offered for the 2006 HIV testing methods, and to measure the extent to which patients and clinicians favored the 2001 HIV testing methods. Models were adjusted for participant age, gender, race/ethnicity, HIV testing history, and study arm (for Part I only). The interaction (i.e., synergy or effect modification) between participant type (clinician vs. patient) and randomized group (2006 vs. 2001 HIV testing methods) was the primary outcome of interest for the ethical concerns models. For all models, we estimated odds ratios (ORs) with corresponding 95% CIs.

## RESULTS

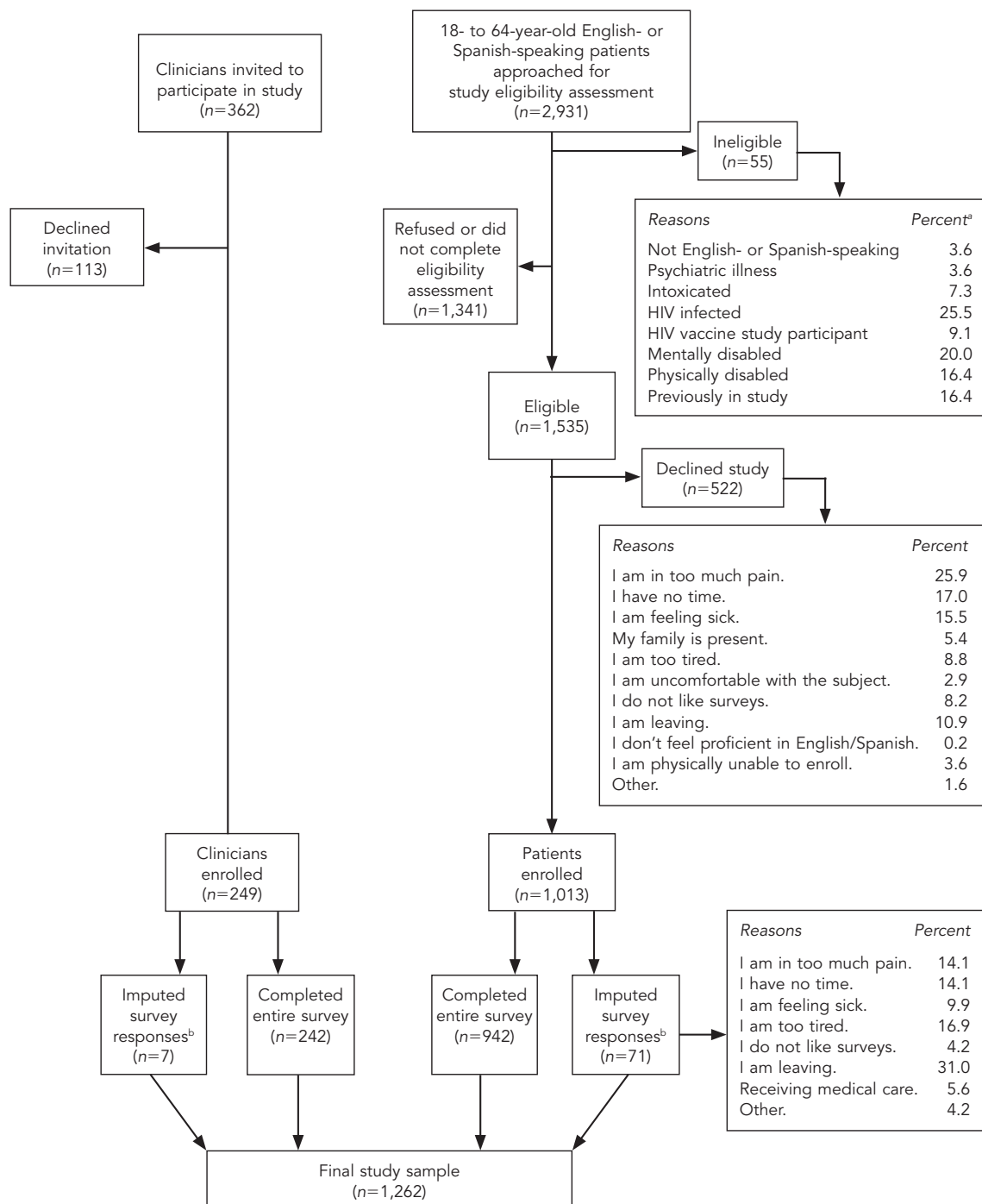
### Participant enrollment and characteristics

The final sample of 1,262 participants included 1,013 (80.3%) patients and 249 (19.7%) clinicians. Figure 1 depicts the flow of participant eligibility assessment, recruitment, enrollment, and study completion. Few patients (2.9%) declined participation because of the subject of the study. As compared with clinicians, patients were older, more ethnically/racially diverse, and more likely to have been tested for HIV through blood donation, screening, or diagnostic testing (Table).

### Ethical concerns about the 2006 CDC HIV testing methods

Clinicians and patients differed on their perspectives about whether the 2006 CDC HIV testing methods were as morally acceptable as the 2001 testing methods (Figure 2). Among clinicians, when each ethical concern was considered individually, the 2006 methods were considered to be less morally acceptable (i.e., inferior) than the 2001 methods for eight of the nine

**Figure 1. Eligibility assessment, enrollment, and study completion diagram for a randomized controlled trial evaluating ethical concerns about the 2006 vs. 2001 CDC HIV testing methods at three hospitals in Rhode Island, June–December 2007**



<sup>a</sup>Reasons for ineligibility do not total 100% because multiple reasons for ineligibility were possible.

<sup>b</sup>Participants completed a portion of the survey; missing responses were imputed.

CDC = Centers for Disease Control and Prevention

HIV = human immunodeficiency virus

**Table. Comparison of demographic characteristics and HIV testing history of patients vs. clinicians who participated in a randomized controlled trial at three hospitals in Rhode Island, June–December 2007**

| Variables                                          | Patients<br>(n=1,013)<br>Percent | Clinicians<br>(n=249)<br>Percent | P-value <sup>a,b</sup> |
|----------------------------------------------------|----------------------------------|----------------------------------|------------------------|
| Demographic characteristics                        |                                  |                                  |                        |
| Median age (in years) (interquartile range)        | 38 (28–48)                       | 35 (29–39)                       | 0.001                  |
| Gender                                             |                                  |                                  | 0.163                  |
| Female <sup>c</sup>                                | 55.5                             | 50.6                             |                        |
| Male                                               | 44.5                             | 49.4                             |                        |
| Race/ethnicity                                     |                                  |                                  | 0.001                  |
| Non-Hispanic white                                 | 46.9                             | 75.9                             |                        |
| Hispanic white                                     | 19.9                             | 3.2                              |                        |
| Non-Hispanic black/African American                | 19.8                             | 1.2                              |                        |
| Hispanic black                                     | 10.2                             | 0.0                              |                        |
| Asian/Middle Eastern                               | 1.1                              | 14.9                             |                        |
| American Indian/Alaska Native                      | 1.7                              | 0.0                              |                        |
| Other race/ethnicity                               | 0.4                              | 4.8                              |                        |
| HIV testing history                                |                                  |                                  |                        |
| Ever tested for HIV (not part of a blood donation) |                                  |                                  | 0.001                  |
| Previously tested for HIV                          | 70.2                             | 66.3                             |                        |
| Never tested for HIV                               | 29.8                             | 32.1                             |                        |
| Don't know                                         | 0.0                              | 1.6                              |                        |
| Time elapsed since last HIV test                   |                                  |                                  | 0.001                  |
| >5 years                                           | 21.2                             | 31.5                             |                        |
| >2 years but ≤5 years                              | 16.9                             | 25.5                             |                        |
| >1 year but ≤2 years                               | 19.7                             | 10.9                             |                        |
| >6 months but ≤1 year                              | 23.5                             | 13.9                             |                        |
| <6 months                                          | 18.7                             | 17.6                             |                        |
| Don't know                                         | 0.0                              | 0.6                              |                        |
| Ever donated blood                                 |                                  |                                  | 0.001                  |
| Yes                                                | 30.4                             | 64.3                             |                        |
| No                                                 | 69.6                             | 35.7                             |                        |
| Time elapsed since last blood donation             |                                  |                                  | 0.006                  |
| >5 years                                           | 53.5                             | 52.5                             |                        |
| >2 years but ≤5 years                              | 15.2                             | 28.1                             |                        |
| >1 year but ≤2 years                               | 10.9                             | 6.2                              |                        |
| >6 months but ≤1 year                              | 8.9                              | 5.6                              |                        |
| <6 months                                          | 11.6                             | 7.5                              |                        |
| History of any HIV test                            |                                  |                                  | 0.001                  |
| Tested, but not part of a blood donation           | 48.6                             | 21.7                             |                        |
| Tested as part of a blood donation                 | 8.8                              | 19.7                             |                        |
| Tested and donated blood                           | 21.6                             | 44.6                             |                        |
| No known HIV test                                  | 21.0                             | 13.7                             |                        |
| Don't know                                         | 0.0                              | 0.4                              |                        |

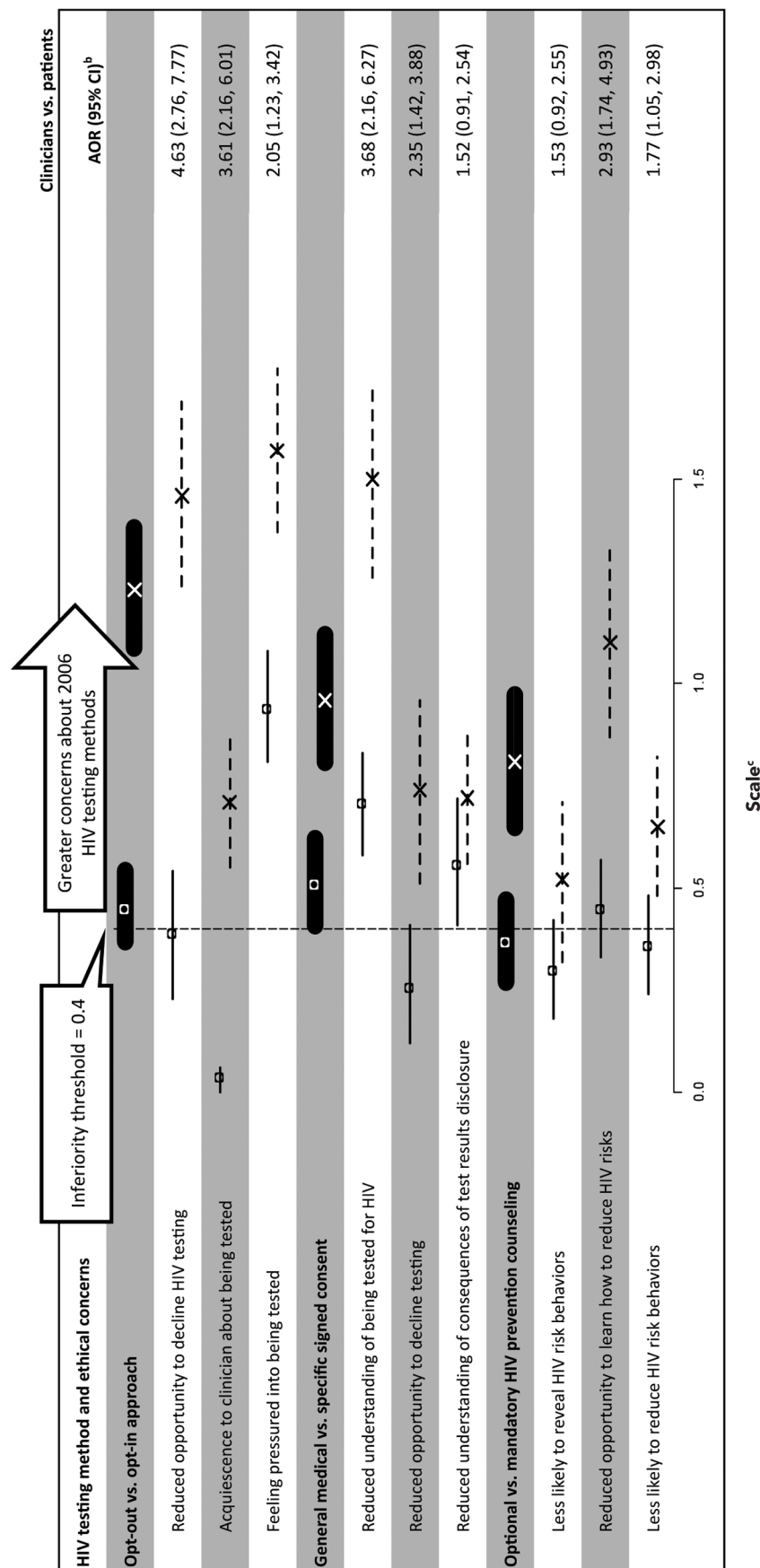
<sup>a</sup>Wilcoxon sign-rank testing for continuous variables and Pearson's Chi-square testing for categorical variables<sup>b</sup>P-values reflect comparison of characteristics of patients vs. clinicians.<sup>c</sup>Includes one male-to-female transgender who self-identified as female

HIV = human immunodeficiency virus

ethical concerns. Among patients, the 2006 methods were considered to be inferior for three of the nine ethical concerns. As shown by the results of the multivariable regression analysis, the effect between participant group (clinicians vs. patients) and study arm assignment (2006 vs. 2001 methods) was synergistic

or multiplicative, and not just additive (i.e., exhibited effect measure modification). In other words, clinicians viewing the 2006 CDC HIV testing methods generally had greater concerns than clinicians viewing the 2001 testing methods as well as patients in both study arms. When the three concerns for each HIV testing method

**Figure 2. Ethical concerns about the 2006 vs. 2001 CDC HIV testing methods by patients and clinicians in a randomized controlled trial at three hospitals in Rhode Island, June–December 2007<sup>a</sup>**



<sup>a</sup>The circles (O) and crosses (X) represent the point estimates of the difference in concerns between study arm assignment (2006 vs. 2001 CDC HIV testing methods) for patients and clinicians, respectively, with corresponding 95% CIs. The thick bars are the aggregated concerns for each of the three HIV testing methods.

<sup>b</sup>The AORs represent the interaction between study arm assignment (2006 vs. 2001 HIV testing strategies) and participant type (clinicians vs. patients). Higher AORs indicate a greater concern by clinicians about the 2006 HIV testing strategies. Odds ratios were adjusted for age, gender, race/ethnicity, study arm assignment, and history of ever having been tested for HIV.

<sup>c</sup>The scale represents the magnitude of the difference in ethical concerns for the 2006 vs. 2001 CDC HIV testing methods.

CDC = Centers for Disease Control and Prevention

HIV = human immunodeficiency virus

AOR = adjusted odds ratio

CI = confidence interval



were aggregated, clinicians had greater concerns about the opt-out approach than they did about the use of general medical consent and optional HIV prevention counseling, whereas patients considered the 2006 methods to be as morally acceptable as the 2001 methods.

#### **Ethical justifications for the 2006 CDC HIV testing methods**

Clinicians indicated much greater support for the justifications made for implementing two of the 2006 HIV testing methods (opt-out approach and general medical consent) than patients (Figure 3). Patients were more supportive than clinicians of the justifications made for using optional rather than mandatory HIV prevention counseling. Clinicians believed that the opt-out approach would lead to a greater increase in people undergoing HIV testing and destigmatizing HIV testing than the other two testing methods. Patients regarded the three testing methods as having a similar effect on increasing HIV testing, but they viewed the opt-out approach as more likely to destigmatize HIV testing.

#### **Preferences for the 2006 or 2001 CDC HIV testing methods**

Both patients and clinicians had greater preferences for the 2001 than the 2006 CDC HIV testing methods (Figure 4). Clinicians showed a relatively greater preference for the opt-out approach and use of general medical consent than patients, while patients had a relatively greater preference for optional HIV prevention counseling. Clinician preference was highest for mandatory HIV prevention counseling compared with the other two methods, whereas patient preference was highest for optional HIV prevention counseling.

## **DISCUSSION**

In this study population, patients generally viewed the three 2006 CDC HIV testing methods (opt-out approach, general medical consent, and optional prevention counseling) as being as morally acceptable as the 2001 testing methods (opt-in approach, specific signed consent, and mandatory prevention counseling). In contrast, clinicians generally found the 2006 testing methods to be relatively more ethically concerning than did patients. Yet, their level of concern varied by testing method and was low for most concerns evaluated (e.g., the largest difference was 1.57 on a 0–4 point scale). In fact, although clinicians considered the opt-out approach and use of general medical consent as relatively more ethically troubling than did patients, they were more apt than patients to support the justifications cited in support of the opt-

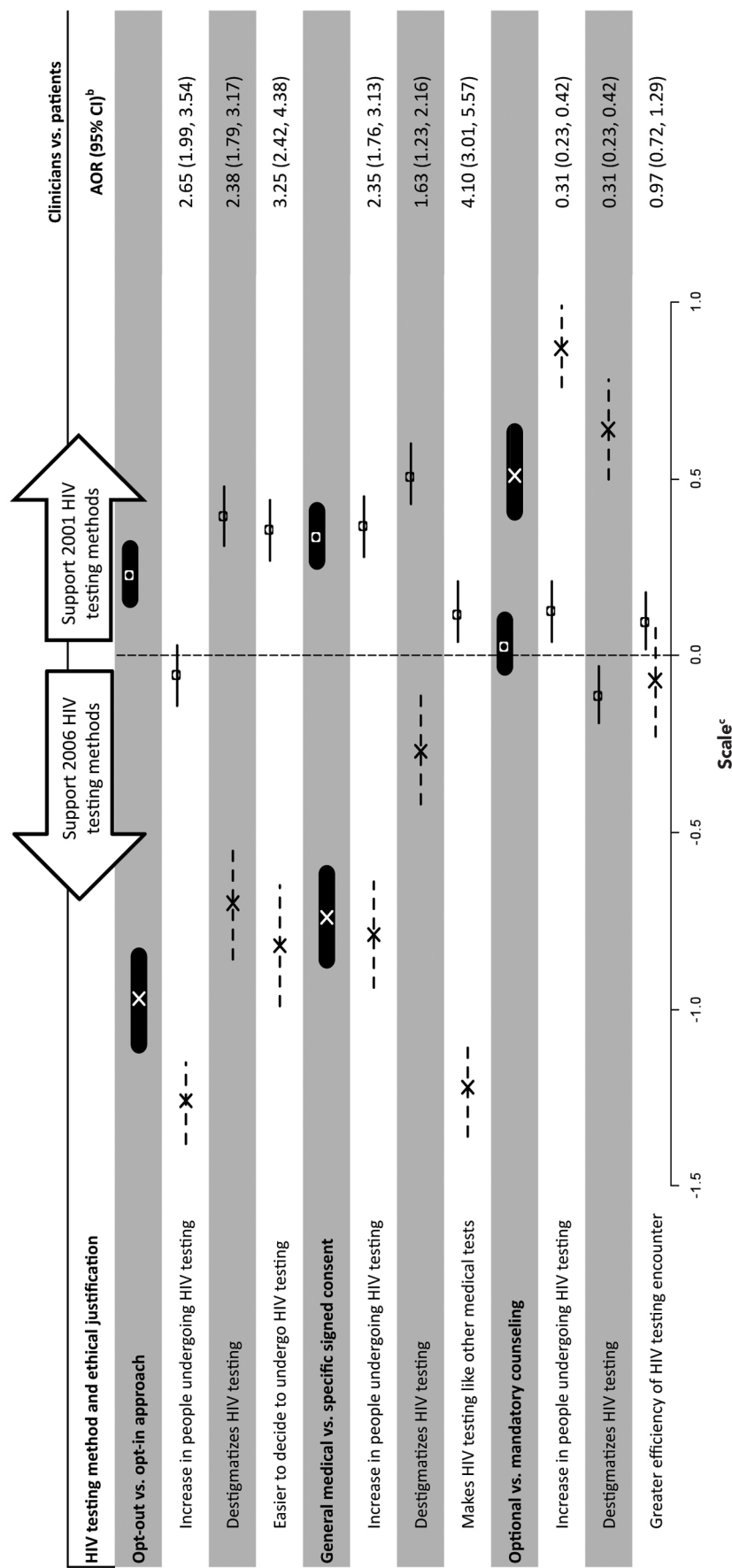
out approach and use of general medical consent and had a relatively greater preference for these two testing methods. Unlike their clinicians, patients indicated less support for the justifications made for the opt-out approach and use of the general medical consent, and had a relatively greater preference for optional prevention counseling. We did not assess the reasons for the divergent views between clinicians and patients, but the differences might be explained by clinicians' experience in using the 2001 HIV testing methods. Clinicians perhaps also hold more of a public health and health delivery view of HIV testing, while patients have a consumer's view. Alternatively, clinicians might have some knowledge of the debate over the 2006 CDC HIV testing methods in the medical literature. It is unclear if this divergence will decrease or become more pronounced as more clinicians implement and patients experience the 2006 testing methods firsthand.

It is interesting to observe that clinicians appear to have a more conservative perspective than patients regarding the ethical concerns raised about the 2006 recommendations, which bodes poorly for their planned implementation. The results show that CDC still must address ethical concerns about its 2006 methods among clinicians who are being asked to implement them. The study results also indicate that, at least among this sample, patients are not yet persuaded by the ethical justifications offered for the 2006 HIV testing methods. If patients are not convinced about the merits of the recommended methods, and clinicians have ethical concerns about them, then the hope for their implementation might not be fully realized. As a consequence, the subsequent increase in HIV testing with resultant increase in linkage to care and reduction in HIV transmission might not occur. If clinicians do not think the methods are right for patients, despite their beliefs in how they might be justified, they might not employ them, even if patients do not have objections to them.

#### **Limitations**

Our study was subject to a number of limitations. First, it did not address the legal or operational challenges to the 2006 CDC recommendations and did not determine if the 2006 CDC HIV testing methods are morally sound or troublesome. Second, the study was conducted in a state that had not yet enacted the 2006 CDC HIV testing recommendations, so experience with the 2006 HIV testing methods was likely limited. However, it is arguable that this state might be the ideal setting in which to assess the ethical concerns and justifications made for new public health policies. Third, because the study was conducted at academic

**Figure 3. Ethical justifications for the 2006 vs. 2001 CDC HIV testing methods by patients and clinicians in a randomized controlled trial at three hospitals in Rhode Island, June–December 2007<sup>a</sup>**

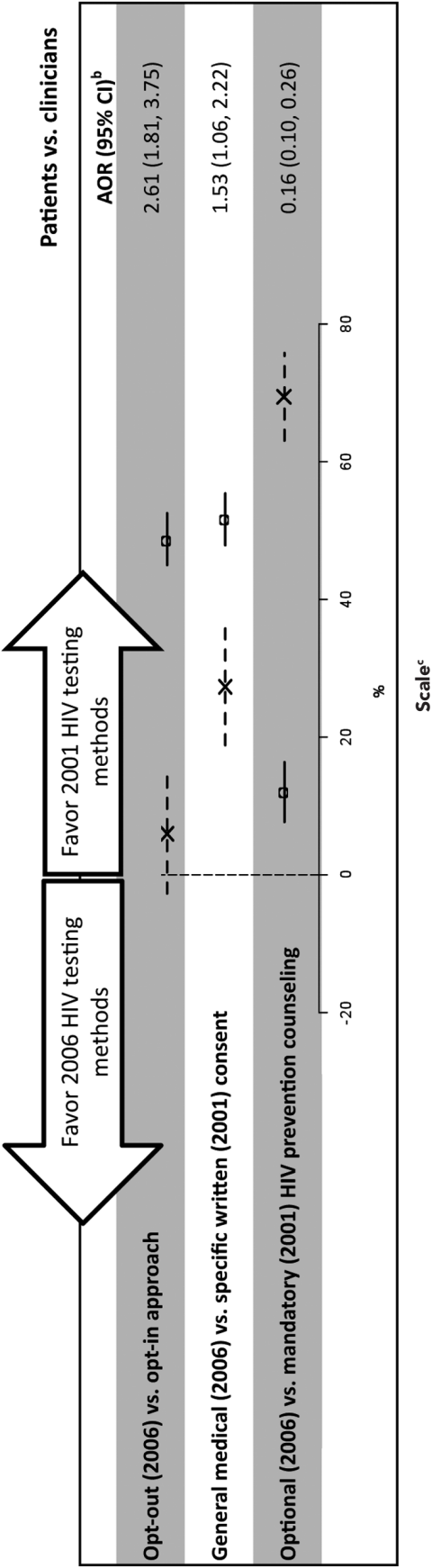


<sup>a</sup>The circles (O) and crosses (X) represent the point estimates of the level of support for the ethical justifications by patients and clinicians, respectively, with corresponding 95% CIs. The thick bars are the aggregated concerns for each of the three HIV testing methods.

<sup>b</sup>The AORs represent the greater belief in justifications by clinicians. Odds ratios were adjusted for age, gender, race/ethnicity, and history of ever having been tested for HIV.

<sup>c</sup>The scale represents the magnitude of the mean level of support participants indicated for ethical justifications for the 2006 vs. the 2001 CDC HIV testing methods (on a scale from -1.5 to 1.0).  
 CDC = Centers for Disease Control and Prevention  
 HIV = human immunodeficiency virus  
 AOR = adjusted odds ratio  
 CI = confidence interval

**Figure 4. Preferences for the 2006 or 2001 CDC HIV testing methods by patients and clinicians in a randomized controlled trial at three hospitals in Rhode Island, June–December 2007<sup>a</sup>**



<sup>a</sup>The circles (O) and crosses (X) represent the point estimates of the difference in preferences by patients and clinicians, respectively, with corresponding 95% CIs.

<sup>b</sup>The AORs represent greater preferences by patients for the 2001 HIV testing methods. Odds ratios were adjusted for age, gender, race/ethnicity, and history of ever having been tested for HIV.

<sup>c</sup>The scale represents the mean level of support participants indicated for ethical justifications for the 2006 vs. the 2001 CDC HIV testing methods (on a scale from -20 to 80).

CDC = Centers for Disease Control and Prevention

HIV = human immunodeficiency virus

AOR = adjusted odds ratio

CI = confidence interval

institutions, it is unclear how well these findings can be generalized to non-academic institutions, as testing practices, clinician perspectives, patient demographic characteristics, and HIV prevalence might vary between these types of institutions. Furthermore, we cannot assess the viewpoints of the clinicians and patients who declined to participate or were ineligible for the study.

Fourth, it is possible that participants did not understand the ethical concerns or justifications examined in the study, despite cognitive-based assessments demonstrating patient comprehension of the concepts and questions, the ACASI format, and efforts to construct the survey to assess viewpoints rather than prior knowledge about the topics addressed. Regardless, any possible misunderstandings might account for some of the differences between clinicians and patients.

## CONCLUSIONS

We believe that there are important differences in perspectives between patients and their clinicians in regard to concerns raised about, justifications offered regarding, and preferences for the 2006 CDC HIV testing methods. These differences should at least be addressed in the form of educational campaigns and clarifications so that testing efforts are not compromised. The results indicate an opportunity to review not only these but also future HIV testing recommendations, as well as how they are presented for implementation.

This study was approved by the Institutional Review Boards of Memorial Hospital of Rhode Island, The Miriam Hospital, and Rhode Island Hospital. Preliminary findings from this research were presented at the 2008 National Summit on HIV Diagnosis, Prevention, and Access to Care in Arlington, Virginia; the 2009 Centers for Disease Control and Prevention National HIV Prevention Conference in Atlanta; and the 2009 Society for Academic Emergency Medicine Annual Meeting in New Orleans.

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# Patient and Clinician Ethical Perspectives on the 2006 Centers for Disease Control and Prevention HIV Testing Methods

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## ABSTRACT

**Objectives.** CDC 2006 recommendations for new HIV testing methods in U.S. health-care settings (opt-out approach, general medical consent, and optional prevention counseling) have been the subject of a public ethical debate. Ethical concerns might limit their implementation and affect expanded HIV screening efforts. We compared clinicians' and patients' perspectives on the ethical concerns raised about, justifications provided in support of, and preferences for the 2006 CDC-recommended HIV testing methods for the U.S. health-care setting, in contrast with the 2001 CDC-recommended HIV testing methods (opt-in approach, specific written consent, and mandatory prevention counseling).

**Methods.** We conducted a non-inferiority trial and survey of 249 clinicians and random samples of 1,013 of their patients at three emergency departments and three ambulatory care clinics at university-affiliated hospitals in Rhode Island from June to December 2007.

**Results.** Clinicians found the 2006 CDC HIV testing methods to be more ethically concerning than the 2001 testing methods (i.e., ethically inferior), while patients had few ethical concerns. In regard to ethical justifications cited for the 2006 CDC HIV testing methods, clinicians were more supportive of the ethical justifications cited for using an opt-out approach and general medical consent, while patients were more supportive of the justifications for optional HIV prevention counseling. Clinicians showed a relatively greater preference for the opt-out approach and use of general medical consent, while patients had a relatively greater preference for optional HIV prevention counseling.

**Conclusions.** Clinicians and their patients hold divergent ethical perspectives on CDC's 2006 HIV testing methods. The results indicate an opportunity to review not only these but also future HIV testing recommendations, as well as how they are presented for implementation.

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In September 2006, the Centers for Disease Control and Prevention (CDC) released revised recommendations for human immunodeficiency virus (HIV) testing in U.S. clinical settings.<sup>1</sup> The 2006 recommendations, as compared with those from 2001,<sup>2</sup> contained three substantial changes in HIV testing methods, which elicited considerable ethical debate. For these changes, CDC recommended the use of (1) an opt-out instead of an opt-in approach to initiating HIV testing, (2) general medical consent instead of specific signed consent for HIV testing, and (3) optional rather than mandatory prevention counseling at the time of HIV testing. CDC believed that use of these new methods was ethically justified because their implementation would ultimately lead to a reduction in HIV transmission by increasing HIV testing and facilitating linkage to care for those who are HIV infected.<sup>1</sup> However, some leaders in HIV care and advocacy expressed ethical concerns about these new HIV testing methods.<sup>3–15</sup> These concerns included doubts that patients would be duly informed about being tested, might be tested without consent, and might lose opportunities for counseling to reduce their risk of acquiring an HIV infection.

It is unknown to what extent clinicians and their patients agree with the ethical concerns voiced about CDC's 2006 HIV testing methods or believe that their implementation is ultimately morally justified. Concerns about the testing methods and skepticism about the justifications offered in support of them could adversely affect the success of increasing HIV testing in the United States. Furthermore, if patients and clinicians differ in their beliefs about the moral acceptability of the 2006 testing methods, there could be conflicts that might undermine the clinician-patient trust, which could reduce patients' willingness to be tested for HIV. Although minor concerns about the testing methods and differences in perspectives between patients and clinicians might be overcome by education, time, and experience, major concerns and conflicts might indicate the need for further changes in HIV testing methods. Concerns about prior CDC HIV testing recommendations from the early years of the epidemic led to substantial changes in testing methods.<sup>2,16–18</sup> Understanding the moral acceptability of CDC's 2006 recommendations for health-care settings is particularly timely given CDC's plan to release new recommendations for HIV testing in nonclinical settings.<sup>19</sup>

The primary objectives of this study were to investigate if (1) clinicians and their patients believe that the three CDC 2006 HIV testing methods are ethically concerning and (2) the testing methods can accomplish the justifications cited in support of their imple-

mentation. We were particularly interested in finding out if patients and their clinicians found the 2006 HIV testing methods at least as morally acceptable as (i.e., not ethically inferior to) the HIV testing methods CDC previously recommended in 2001. Further, we aimed to determine to what extent clinicians and patients differed on their perspectives about and their preferences for the 2006 vs. 2001 CDC-recommended HIV testing methods.

## METHODS

### Study setting

This study enrolled patients and their clinicians from June to December 2007 at six study sites located within three academic hospitals (Memorial Hospital of Rhode Island, The Miriam Hospital, and Rhode Island Hospital) affiliated with the Alpert Medical School of Brown University. The three hospitals are engaged in teaching programs for medical students, residents, and fellows. The six study sites at the three hospitals were three emergency departments (EDs), two internal medicine clinics, and one family medicine clinic. HIV prevalence in Rhode Island's general population is approximately 0.3%, which is similar to the national average.<sup>20</sup> Our prior research identified an HIV prevalence of <1% among 18- to 64-year-old Rhode Island Hospital ED patients.<sup>21</sup> HIV prevalence at the other study sites has not been estimated.

### Study population

All clinicians (i.e., attending, fellow, and resident physicians; nurse practitioners; and physician assistants) who worked at the EDs and clinics at the six study sites were invited to participate. A random sample of 18- to 64-year-old English- or Spanish-speaking patients at the study sites were assessed for study eligibility, and those who were eligible were invited to participate. Patients were excluded if they were critically ill or injured, inmates or on home confinement, known to be HIV infected, participants in an HIV vaccine study, or unable to provide consent or participate in the study because of an acute psychiatric condition or physical or mental impairment.

For the clinics, we randomly selected dates and times to conduct the study. We approached all patients in the clinic on those random dates and times and assessed their eligibility for the study. For the EDs, we randomly selected dates and times to collect data for the study based upon the typical patterns of patient registration to these EDs, using sampling methods performed in our previous studies.<sup>22,23</sup> Accordingly, 40% of the eight-hour shifts for data collection were from 8 a.m.

to 4 p.m., 50% were from 4 p.m. to 12 a.m., and 10% were from 12 a.m. to 8 a.m. Due to the much larger number of patients available to approach in the ED vs. clinic settings, we also randomly selected patients present in the ED during those shifts to approach for an assessment of their study eligibility and possible enrollment.

### Development of study instruments

We developed the “Ethical Perspectives on the 2006 CDC HIV Testing Recommendations Questionnaire” specifically for this study (available from: URL: [http://www.research.brown.edu/pdf/Ethical\\_Perspectives\\_on\\_the\\_2006\\_CDC\\_HIV\\_Testing\\_Recommendations\\_Questionnaire.doc](http://www.research.brown.edu/pdf/Ethical_Perspectives_on_the_2006_CDC_HIV_Testing_Recommendations_Questionnaire.doc)). The questionnaire was developed by our multidisciplinary research team of emergency medicine, family medicine, internal medicine, and HIV specialist clinicians; a philosopher-bioethicist; a survey methodologist; an epidemiologist; and a biostatistician. From our review of the 2006 CDC recommendations, research conducted, and commentaries published in the lay and medical literature on this topic,<sup>24</sup> we identified recurring ethical concerns about and justifications for the three 2006 HIV testing methods (opt-out approach, general medical consent, and optional prevention counseling). We created the questionnaire based upon these concerns and justifications.

We conducted cognitive-based assessments of the English- and Spanish-language versions of the questionnaire to assess and revise the questions, instructions, and accompanying images in an iterative fashion using techniques recommended by other investigators.<sup>25–28</sup> For these assessments, we enrolled five female and five male attending physicians and residents at a hospital affiliated with our medical school, but not a part of the study, and five English- and five Spanish-speaking 18- to 64-year-old patients at each of the six study sites. We enrolled an equal number of patients based upon age group (18–33, 34–49, and 50–64 years of age), gender, race (white or nonwhite), and years of formal education (<12 years, 12 years, or >12 years). Participants in the cognitive-based assessments received a \$15 gift card to a local pharmacy.

### Study instruments description and instrument administration

The questionnaire consists of three parts that correspond to concerns (Part I), justifications (Part II), and preferences (Part III). For Part I, participants were randomly assigned to view a fictional scenario in which a clinician employed either the 2006 or the 2001 CDC-recommended testing methods for each of the three typical phases of the HIV testing process:

(1) initiating HIV testing (opt-out [2006] vs. opt-in [2001] approach); (2) obtaining consent for HIV testing (general medical [2006] vs. specific signed [2001] consent); and (3) offering prevention counseling (optional [2006] vs. mandatory [2001]). Participants were asked questions about the scenario they viewed. The questions measured the extent to which the participants agreed with the moral concerns raised in the lay and medical literature about the three 2006 CDC testing methods. Participants were randomly assigned to view either a 2006 or a 2001 scenario for each phase of the testing process, so that they would consider each phase of the testing process separately and not believe that the scenarios presented from each phase were linked. Accordingly, because there were two methods to view for three phases, there were eight possible randomization patterns. For purposes of analysis, participants were grouped into two study arms (2006 or 2001 testing method) for each of the three phases. Block randomization was used for the assignments for Part I by study site.

In Part II, participants were shown both the 2006 and 2001 HIV testing method fictional scenarios from Part I simultaneously. They were asked to compare the scenarios in accompanying questions that measured the extent to which they agreed with the ethical justifications for the 2006 CDC testing methods. In Part III, participants again were shown both scenarios from Part I simultaneously and asked to indicate which HIV testing method they preferred for each phase of the HIV testing process. Participants were also asked about their demographic characteristics and HIV testing history using questions developed for previous studies.<sup>23,29</sup> Responses to all questionnaires were anonymous.

The scenarios and questions were purposely designed to enable those without prior knowledge or experience with either the 2006 or the 2001 CDC HIV testing methods to provide their perspectives. Participants viewed the scenarios as if they were an observer and not someone administering or receiving the testing method. They were not informed which scenario represented either the 2006 or the 2001 HIV testing methods, and which methods were currently recommended by CDC. Participants were not informed of any controversy about or justifications for the HIV testing methods being displayed.

Patients completed the study in the waiting and treatment rooms of the ambulatory care clinics and EDs. Patients were administered the questionnaire using an audio computer-assisted self-interviewer (ACASI) system by which they viewed the scenarios and listened to professional audio voice recordings of the study questions and instructions. Patients were not offered an

incentive for participating but were invited to undergo free rapid HIV testing after completing the study. Clinicians received e-mail, mail, and verbal notices and reminders about the study and were given a \$5 gift card to a local store as an incentive for participating. Clinicians who completed the study were entered into a lottery to win a prize worth \$125. Most participants completed the survey within 10–15 minutes.

### Data analysis

Summary statistics (e.g., means, proportions, and 95% confidence intervals [CIs]) were computed for study eligibility assessment, enrollment, and participation, and for responses to the study instruments. Missing responses to the ethical perspectives questionnaire were imputed using the demographic characteristics as predictor variables per recommended multivariable regression techniques.<sup>30</sup> We compared demographic characteristics and HIV testing history of patients vs. clinicians using Wilcoxon signed-rank tests for continuous variables and Pearson's Chi-square tests for categorical variables. Differences at the  $\alpha=0.05$  level were considered significant for all analyses.

For Part I of the study, we examined if participants believed that the 2006 CDC HIV testing methods had the same level of ethical concerns as the 2001 CDC HIV testing methods (i.e., considered the 2006 CDC HIV testing methods to be similar [i.e., not inferior] to the 2001 testing methods in regard to ethical concerns). We used a non-inferiority approach to test whether or not differences in the level of ethical concerns between participants assigned to the two study arms (2006 vs. 2001 testing methods) by testing phase (opt-out vs. opt-in approach, general medical vs. specific signed consent, optional vs. mandatory HIV prevention counseling) were small. For non-inferiority studies, a 10% reduction in the lower limit of the mean of the values measured for the reference study arm (in this case, the 2001 HIV testing methods) is typically used as the criterion for non-inferiority.<sup>31</sup> Accordingly, we established a uniform standard for establishing non-inferiority for each concern evaluated in Part I of the questionnaire. Because the scale measuring the level of concerns in Part I ranged from 0 (no concern) to 4 (high level of concern) points, we established that a <10% difference between study arms (0.4 points) would be the non-inferiority criterion. We calculated the difference in means to the responses to the concerns tested in Part I between study arms, along with corresponding 95% CIs. We estimated a priori that at least 332 participants in each study arm would be required ( $\alpha=0.05$ ,  $\beta=0.01$ ) to determine non-inferiority in Part I, which was the primary aim of the study.

For Part II of the study, we calculated the mean and corresponding 95% CI for each response to the questions about justifications for implementing the 2006 vs. 2001 HIV testing methods. The scale for these responses ranged from –2 (greater support for the 2006 HIV testing methods) to +2 (greater support for the 2001 HIV testing methods). If the 95% CI included zero, then both the 2001 and 2006 HIV testing methods were considered to be equally justified. For Part III of the study, we calculated the mean and corresponding 95% CI for the difference in proportions for those who preferred the 2001 vs. 2006 HIV testing methods.

We performed multivariable logistic regression analyses to compare the magnitude of differences in ethical concerns between clinicians and patients about the 2006 vs. 2001 HIV testing methods. We created similar models to compare the extent to which clinicians and patients supported the moral justifications offered for the 2006 HIV testing methods, and to measure the extent to which patients and clinicians favored the 2001 HIV testing methods. Models were adjusted for participant age, gender, race/ethnicity, HIV testing history, and study arm (for Part I only). The interaction (i.e., synergy or effect modification) between participant type (clinician vs. patient) and randomized group (2006 vs. 2001 HIV testing methods) was the primary outcome of interest for the ethical concerns models. For all models, we estimated odds ratios (ORs) with corresponding 95% CIs.

## RESULTS

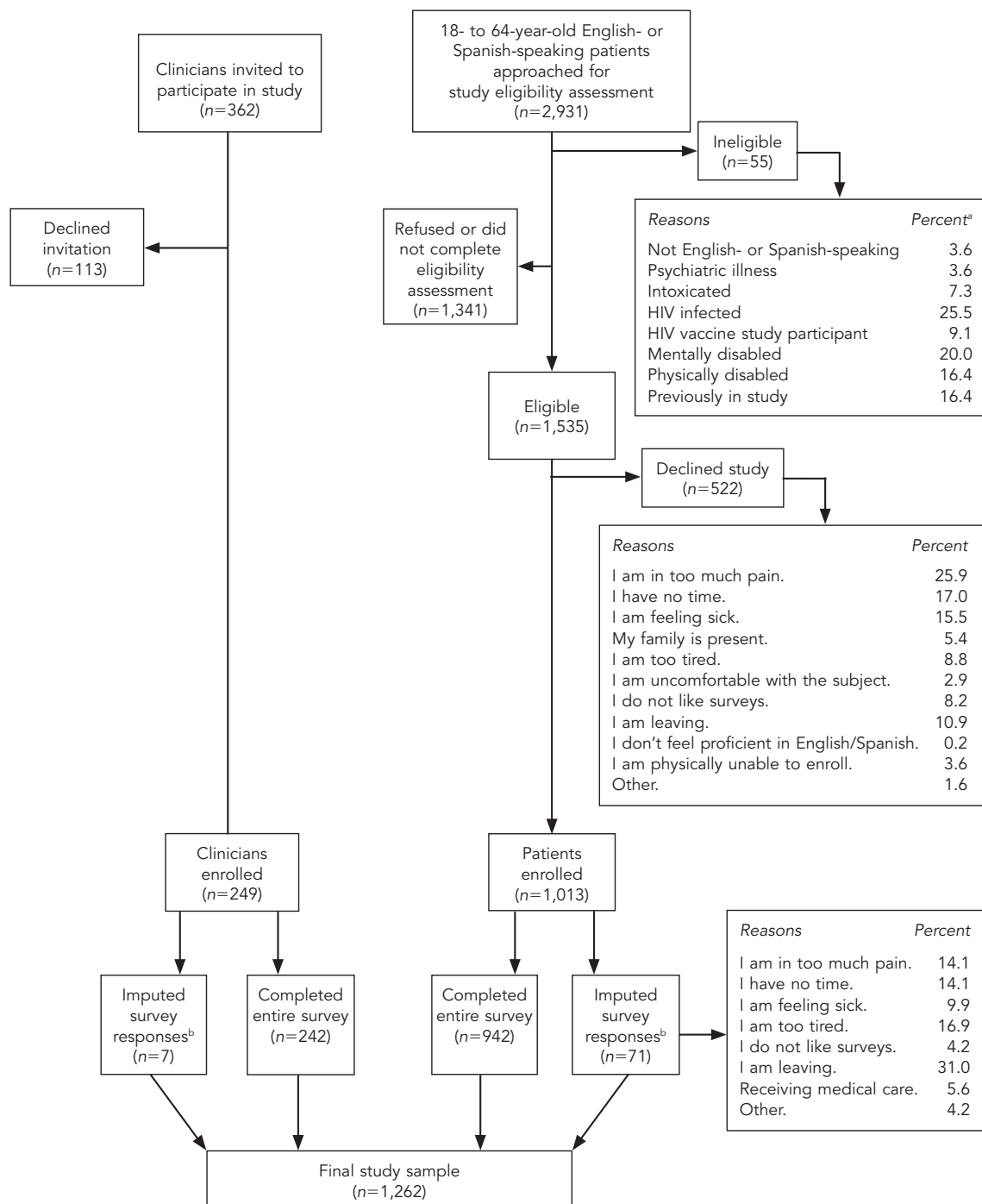
### Participant enrollment and characteristics

The final sample of 1,262 participants included 1,013 (80.3%) patients and 249 (19.7%) clinicians. Figure 1 depicts the flow of participant eligibility assessment, recruitment, enrollment, and study completion. Few patients (2.9%) declined participation because of the subject of the study. As compared with clinicians, patients were older, more ethnically/racially diverse, and more likely to have been tested for HIV through blood donation, screening, or diagnostic testing (Table).

### Ethical concerns about the 2006 CDC HIV testing methods

Clinicians and patients differed on their perspectives about whether the 2006 CDC HIV testing methods were as morally acceptable as the 2001 testing methods (Figure 2). Among clinicians, when each ethical concern was considered individually, the 2006 methods were considered to be less morally acceptable (i.e., inferior) than the 2001 methods for eight of the nine

**Figure 1. Eligibility assessment, enrollment, and study completion diagram for a randomized controlled trial evaluating ethical concerns about the 2006 vs. 2001 CDC HIV testing methods at three hospitals in Rhode Island, June–December 2007**



<sup>a</sup>Reasons for ineligibility do not total 100% because multiple reasons for ineligibility were possible.

<sup>b</sup>Participants completed a portion of the survey; missing responses were imputed.

CDC = Centers for Disease Control and Prevention

HIV = human immunodeficiency virus



**Table. Comparison of demographic characteristics and HIV testing history of patients vs. clinicians who participated in a randomized controlled trial at three hospitals in Rhode Island, June–December 2007**

| Variables                                          | Patients<br>(n=1,013)<br>Percent | Clinicians<br>(n=249)<br>Percent | P-value <sup>a,b</sup> |
|----------------------------------------------------|----------------------------------|----------------------------------|------------------------|
| Demographic characteristics                        |                                  |                                  |                        |
| Median age (in years) (interquartile range)        | 38 (28–48)                       | 35 (29–39)                       | 0.001                  |
| Gender                                             |                                  |                                  | 0.163                  |
| Female <sup>c</sup>                                | 55.5                             | 50.6                             |                        |
| Male                                               | 44.5                             | 49.4                             |                        |
| Race/ethnicity                                     |                                  |                                  | 0.001                  |
| Non-Hispanic white                                 | 46.9                             | 75.9                             |                        |
| Hispanic white                                     | 19.9                             | 3.2                              |                        |
| Non-Hispanic black/African American                | 19.8                             | 1.2                              |                        |
| Hispanic black                                     | 10.2                             | 0.0                              |                        |
| Asian/Middle Eastern                               | 1.1                              | 14.9                             |                        |
| American Indian/Alaska Native                      | 1.7                              | 0.0                              |                        |
| Other race/ethnicity                               | 0.4                              | 4.8                              |                        |
| HIV testing history                                |                                  |                                  |                        |
| Ever tested for HIV (not part of a blood donation) |                                  |                                  | 0.001                  |
| Previously tested for HIV                          | 70.2                             | 66.3                             |                        |
| Never tested for HIV                               | 29.8                             | 32.1                             |                        |
| Don't know                                         | 0.0                              | 1.6                              |                        |
| Time elapsed since last HIV test                   |                                  |                                  | 0.001                  |
| >5 years                                           | 21.2                             | 31.5                             |                        |
| >2 years but ≤5 years                              | 16.9                             | 25.5                             |                        |
| >1 year but ≤2 years                               | 19.7                             | 10.9                             |                        |
| >6 months but ≤1 year                              | 23.5                             | 13.9                             |                        |
| <6 months                                          | 18.7                             | 17.6                             |                        |
| Don't know                                         | 0.0                              | 0.6                              |                        |
| Ever donated blood                                 |                                  |                                  | 0.001                  |
| Yes                                                | 30.4                             | 64.3                             |                        |
| No                                                 | 69.6                             | 35.7                             |                        |
| Time elapsed since last blood donation             |                                  |                                  | 0.006                  |
| >5 years                                           | 53.5                             | 52.5                             |                        |
| >2 years but ≤5 years                              | 15.2                             | 28.1                             |                        |
| >1 year but ≤2 years                               | 10.9                             | 6.2                              |                        |
| >6 months but ≤1 year                              | 8.9                              | 5.6                              |                        |
| <6 months                                          | 11.6                             | 7.5                              |                        |
| History of any HIV test                            |                                  |                                  | 0.001                  |
| Tested, but not part of a blood donation           | 48.6                             | 21.7                             |                        |
| Tested as part of a blood donation                 | 8.8                              | 19.7                             |                        |
| Tested and donated blood                           | 21.6                             | 44.6                             |                        |
| No known HIV test                                  | 21.0                             | 13.7                             |                        |
| Don't know                                         | 0.0                              | 0.4                              |                        |

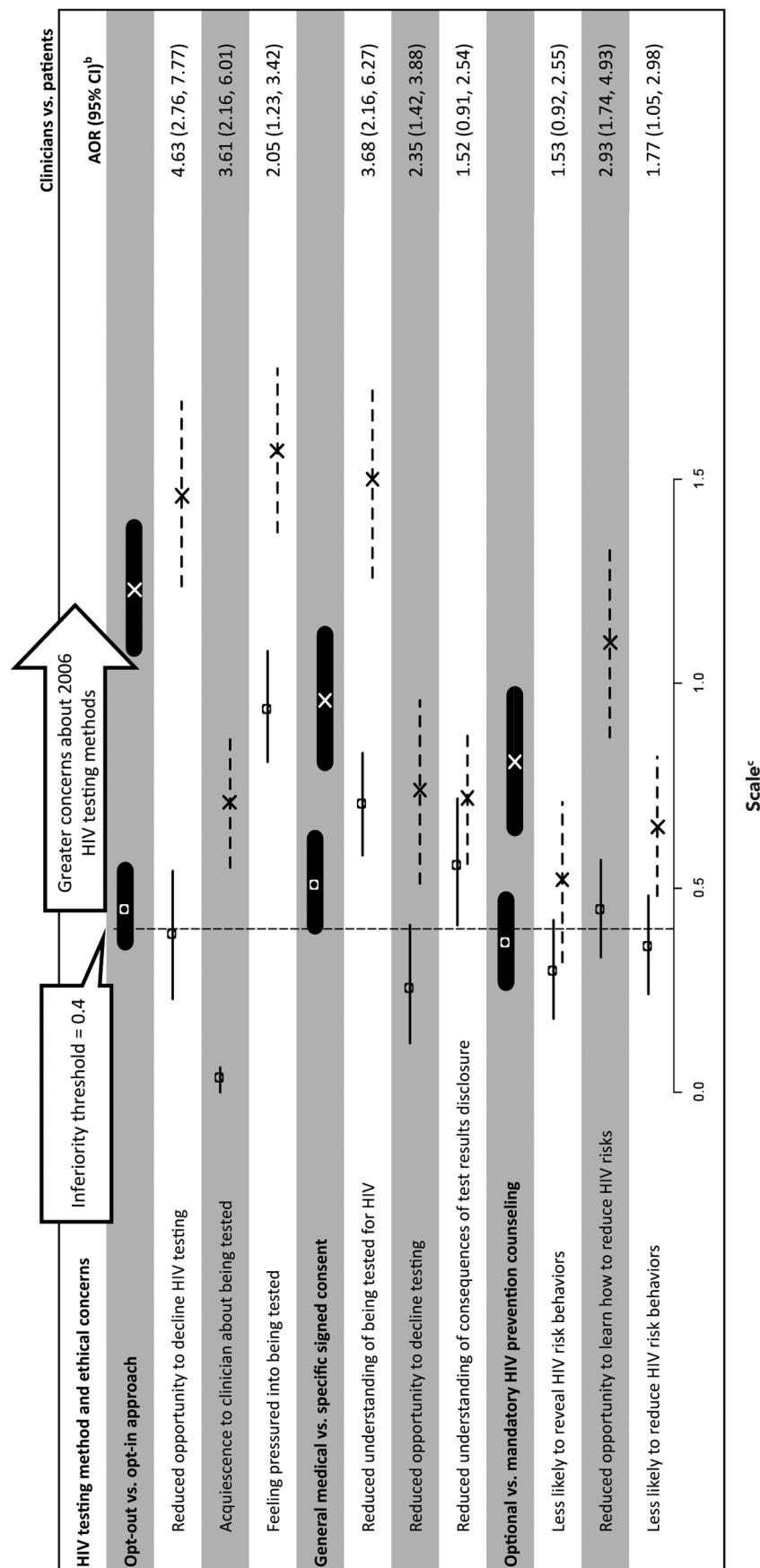
<sup>a</sup>Wilcoxon sign-rank testing for continuous variables and Pearson's Chi-square testing for categorical variables<sup>b</sup>P-values reflect comparison of characteristics of patients vs. clinicians.<sup>c</sup>Includes one male-to-female transgender who self-identified as female

HIV = human immunodeficiency virus

ethical concerns. Among patients, the 2006 methods were considered to be inferior for three of the nine ethical concerns. As shown by the results of the multivariable regression analysis, the effect between participant group (clinicians vs. patients) and study arm assignment (2006 vs. 2001 methods) was synergistic

or multiplicative, and not just additive (i.e., exhibited effect measure modification). In other words, clinicians viewing the 2006 CDC HIV testing methods generally had greater concerns than clinicians viewing the 2001 testing methods as well as patients in both study arms. When the three concerns for each HIV testing method

**Figure 2. Ethical concerns about the 2006 vs. 2001 CDC HIV testing methods by patients and clinicians in a randomized controlled trial at three hospitals in Rhode Island, June–December 2007<sup>a</sup>**



<sup>a</sup>The circles (O) and crosses (X) represent the point estimates of the difference in concerns between study arm assignment (2006 vs. 2001 CDC HIV testing methods) for patients and clinicians, respectively, with corresponding 95% CIs. The thick bars are the aggregated concerns for each of the three HIV testing methods.

<sup>b</sup>The AORs represent the interaction between study arm assignment (2006 vs. 2001 HIV testing strategies) and participant type (clinicians vs. patients). Higher AORs indicate a greater concern by clinicians about the 2006 HIV testing strategies. Odds ratios were adjusted for age, gender, race/ethnicity, study arm assignment, and history of ever having been tested for HIV.

<sup>c</sup>The scale represents the magnitude of the difference in ethical concerns for the 2006 vs. 2001 CDC HIV testing methods.

CDC = Centers for Disease Control and Prevention

HIV = human immunodeficiency virus

AOR = adjusted odds ratio

CI = confidence interval

were aggregated, clinicians had greater concerns about the opt-out approach than they did about the use of general medical consent and optional HIV prevention counseling, whereas patients considered the 2006 methods to be as morally acceptable as the 2001 methods.

#### **Ethical justifications for the 2006 CDC HIV testing methods**

Clinicians indicated much greater support for the justifications made for implementing two of the 2006 HIV testing methods (opt-out approach and general medical consent) than patients (Figure 3). Patients were more supportive than clinicians of the justifications made for using optional rather than mandatory HIV prevention counseling. Clinicians believed that the opt-out approach would lead to a greater increase in people undergoing HIV testing and destigmatizing HIV testing than the other two testing methods. Patients regarded the three testing methods as having a similar effect on increasing HIV testing, but they viewed the opt-out approach as more likely to destigmatize HIV testing.

#### **Preferences for the 2006 or 2001 CDC HIV testing methods**

Both patients and clinicians had greater preferences for the 2001 than the 2006 CDC HIV testing methods (Figure 4). Clinicians showed a relatively greater preference for the opt-out approach and use of general medical consent than patients, while patients had a relatively greater preference for optional HIV prevention counseling. Clinician preference was highest for mandatory HIV prevention counseling compared with the other two methods, whereas patient preference was highest for optional HIV prevention counseling.

## **DISCUSSION**

In this study population, patients generally viewed the three 2006 CDC HIV testing methods (opt-out approach, general medical consent, and optional prevention counseling) as being as morally acceptable as the 2001 testing methods (opt-in approach, specific signed consent, and mandatory prevention counseling). In contrast, clinicians generally found the 2006 testing methods to be relatively more ethically concerning than did patients. Yet, their level of concern varied by testing method and was low for most concerns evaluated (e.g., the largest difference was 1.57 on a 0–4 point scale). In fact, although clinicians considered the opt-out approach and use of general medical consent as relatively more ethically troubling than did patients, they were more apt than patients to support the justifications cited in support of the opt-

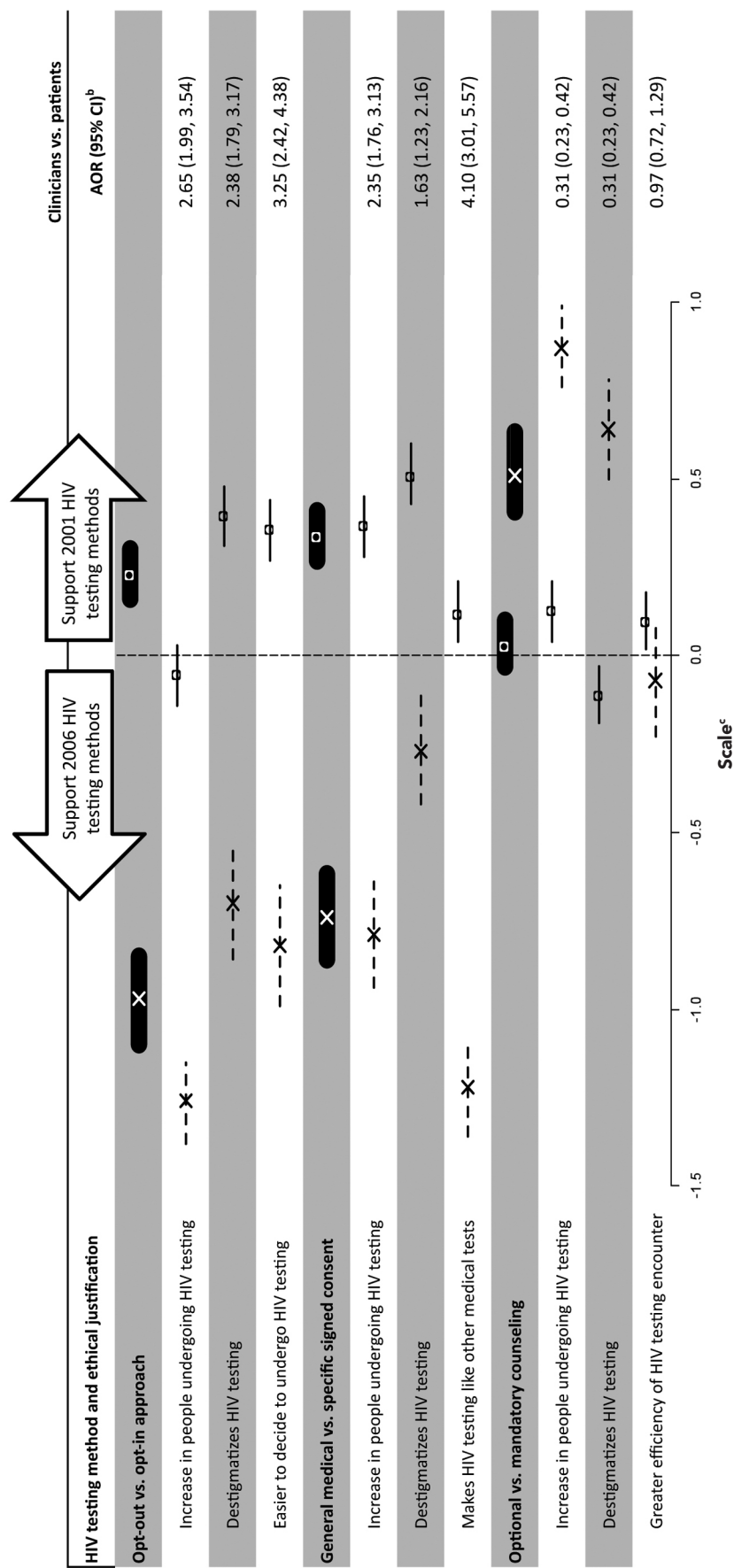
out approach and use of general medical consent and had a relatively greater preference for these two testing methods. Unlike their clinicians, patients indicated less support for the justifications made for the opt-out approach and use of the general medical consent, and had a relatively greater preference for optional prevention counseling. We did not assess the reasons for the divergent views between clinicians and patients, but the differences might be explained by clinicians' experience in using the 2001 HIV testing methods. Clinicians perhaps also hold more of a public health and health delivery view of HIV testing, while patients have a consumer's view. Alternatively, clinicians might have some knowledge of the debate over the 2006 CDC HIV testing methods in the medical literature. It is unclear if this divergence will decrease or become more pronounced as more clinicians implement and patients experience the 2006 testing methods firsthand.

It is interesting to observe that clinicians appear to have a more conservative perspective than patients regarding the ethical concerns raised about the 2006 recommendations, which bodes poorly for their planned implementation. The results show that CDC still must address ethical concerns about its 2006 methods among clinicians who are being asked to implement them. The study results also indicate that, at least among this sample, patients are not yet persuaded by the ethical justifications offered for the 2006 HIV testing methods. If patients are not convinced about the merits of the recommended methods, and clinicians have ethical concerns about them, then the hope for their implementation might not be fully realized. As a consequence, the subsequent increase in HIV testing with resultant increase in linkage to care and reduction in HIV transmission might not occur. If clinicians do not think the methods are right for patients, despite their beliefs in how they might be justified, they might not employ them, even if patients do not have objections to them.

#### **Limitations**

Our study was subject to a number of limitations. First, it did not address the legal or operational challenges to the 2006 CDC recommendations and did not determine if the 2006 CDC HIV testing methods are morally sound or troublesome. Second, the study was conducted in a state that had not yet enacted the 2006 CDC HIV testing recommendations, so experience with the 2006 HIV testing methods was likely limited. However, it is arguable that this state might be the ideal setting in which to assess the ethical concerns and justifications made for new public health policies. Third, because the study was conducted at academic

**Figure 3. Ethical justifications for the 2006 vs. 2001 CDC HIV testing methods by patients and clinicians in a randomized controlled trial at three hospitals in Rhode Island, June–December 2007<sup>a</sup>**

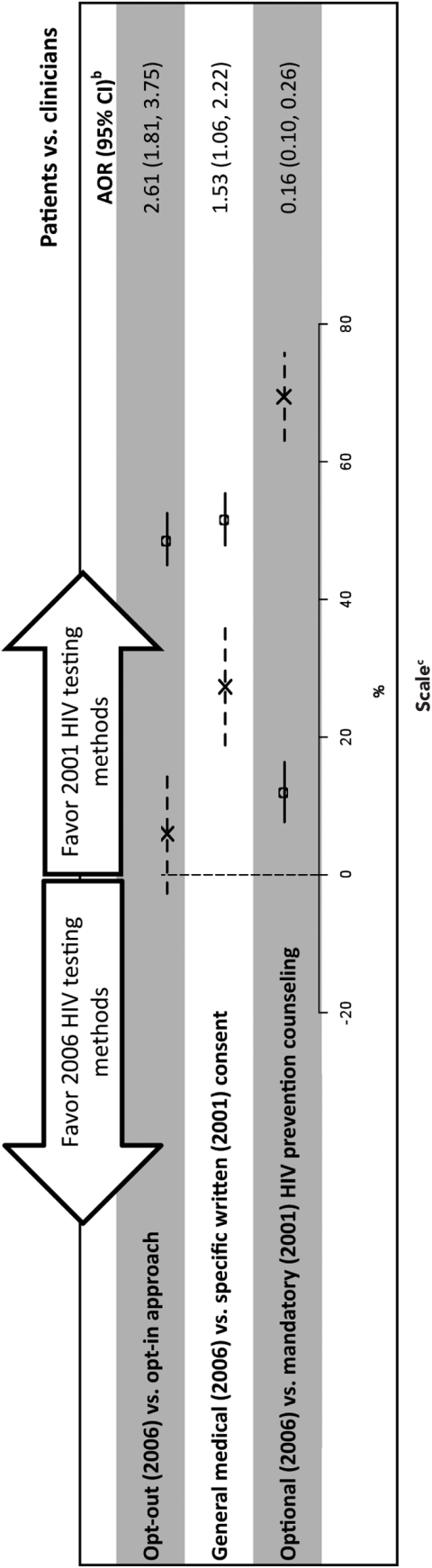


<sup>a</sup>The circles (O) and crosses (X) represent the point estimates of the level of support for the ethical justifications by patients and clinicians, respectively, with corresponding 95% CIs. The thick bars are the aggregated concerns for each of the three HIV testing methods.

<sup>b</sup>The AORs represent the greater belief in justifications by clinicians. Odds ratios were adjusted for age, gender, race/ethnicity, and history of ever having been tested for HIV.

<sup>c</sup>The scale represents the magnitude of the mean level of support participants indicated for ethical justifications for the 2006 vs. the 2001 CDC HIV testing methods (on a scale from -1.5 to 1.0).  
 CDC = Centers for Disease Control and Prevention  
 HIV = human immunodeficiency virus  
 AOR = adjusted odds ratio  
 CI = confidence interval

**Figure 4. Preferences for the 2006 or 2001 CDC HIV testing methods by patients and clinicians in a randomized controlled trial at three hospitals in Rhode Island, June–December 2007<sup>a</sup>**



<sup>a</sup>The circles (O) and crosses (X) represent the point estimates of the difference in preferences by patients and clinicians, respectively, with corresponding 95% CIs.  
<sup>b</sup>The AORs represent greater preferences by patients for the 2001 HIV testing methods. Odds ratios were adjusted for age, gender, race/ethnicity, and history of ever having been tested for HIV.  
<sup>c</sup>The scale represents the mean level of support participants indicated for ethical justifications for the 2006 vs. the 2001 CDC HIV testing methods (on a scale from -20 to 80).  
CDC = Centers for Disease Control and Prevention  
HIV = human immunodeficiency virus  
AOR = adjusted odds ratio  
CI = confidence interval



institutions, it is unclear how well these findings can be generalized to non-academic institutions, as testing practices, clinician perspectives, patient demographic characteristics, and HIV prevalence might vary between these types of institutions. Furthermore, we cannot assess the viewpoints of the clinicians and patients who declined to participate or were ineligible for the study.

Fourth, it is possible that participants did not understand the ethical concerns or justifications examined in the study, despite cognitive-based assessments demonstrating patient comprehension of the concepts and questions, the ACASI format, and efforts to construct the survey to assess viewpoints rather than prior knowledge about the topics addressed. Regardless, any possible misunderstandings might account for some of the differences between clinicians and patients.

## CONCLUSIONS

We believe that there are important differences in perspectives between patients and their clinicians in regard to concerns raised about, justifications offered regarding, and preferences for the 2006 CDC HIV testing methods. These differences should at least be addressed in the form of educational campaigns and clarifications so that testing efforts are not compromised. The results indicate an opportunity to review not only these but also future HIV testing recommendations, as well as how they are presented for implementation.

This study was approved by the Institutional Review Boards of Memorial Hospital of Rhode Island, The Miriam Hospital, and Rhode Island Hospital. Preliminary findings from this research were presented at the 2008 National Summit on HIV Diagnosis, Prevention, and Access to Care in Arlington, Virginia; the 2009 Centers for Disease Control and Prevention National HIV Prevention Conference in Atlanta; and the 2009 Society for Academic Emergency Medicine Annual Meeting in New Orleans.

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# Local Acts

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Disparities in cancer occurrence and cancer outcomes are caused by the disproportionate accrual of risks among racial/ethnic minority, low-income, and uninsured groups across the prevention, detection, and treatment spectrum. Reducing cancer disparities requires efforts in each arena. This article describes one local initiative to improve screening and detection rates among uninsured, low-income, and minority older adults living in Maryland using funding from the Cigarette Restitution Fund. The authors present useful findings on screening volume and results to characterize the impact of the program, indicating that, in addition to the 120 cancers identified, as many as 300 colorectal cancers may have been prevented by polypectomy in the program.

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## EXPERIENCE OF A PUBLIC HEALTH COLORECTAL CANCER TESTING PROGRAM IN MARYLAND

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Colorectal cancer (CRC) was the second leading cause of cancer death among men and women nationally and in Maryland in 2000.<sup>1,2</sup> African Americans in Maryland had an age-adjusted CRC mortality rate that was 1.4 times that of white people (31.1 per 100,000 population vs. 22.1 per 100,000 population for black and white people, respectively).<sup>2</sup> American Cancer Society (ACS) recommendations for CRC screening published in 1997 provided a menu of screening options.<sup>3</sup> Of these, fecal occult blood test (FOBT) and sigmoidoscopy screening have been covered under Medicare Part B since 1998. In 2001, Medicare Part B initiated coverage for colonoscopy screening.<sup>4</sup> In 1999, only 29.1% of Marylanders aged 50–64 years reported having an FOBT in the last year, and only 41.2% had a sigmoidoscopy or colonoscopy within the previous five years.<sup>5</sup> Screening disparities existed with lower screening rates in individuals with lower income, without health insurance, and of minority race/ethnicity.<sup>6</sup>

Although CRC screening has been shown to reduce mortality,<sup>7,8</sup> prior to 2000, only New York State had initiated a public health screening program that used FOBT for screening its low-income uninsured popula-

tion.<sup>9</sup> In 2002, the U.S. Preventive Services Task Force (USPSTF) recommended CRC screening for those aged 50 years and older.<sup>10</sup> Tests and intervals had been further defined by the ACS, and screening test options for those at average risk included (1) annual FOBT, (2) flexible sigmoidoscopy every five years, (3) annual FOBT with flexible sigmoidoscopy every five years, (4) double-contrast barium enema (DCBE) every five years, or (5) colonoscopy every 10 years. While FOBT may detect bleeding from some larger, advanced adenomas and CRCs, non-bleeding lesions can only be found and removed during sigmoidoscopy and colonoscopy. For those at increased risk of CRC or with symptoms, colonoscopy is recommended.

Following the multistate Master Tobacco Settlement Agreement, Maryland established the Cigarette Restitution Fund (CRF) in 2000.<sup>11</sup> The goal of the CRF is to decrease cancer mortality and reduce racial/ethnic disparities in cancer mortality. The Maryland Department of Health and Mental Hygiene (MDHMH) initially developed and now supervises a statewide cancer-control program administered by its local health departments (LHDs). Under the CRF law, each of Maryland's 24 LHDs formed a community health coalition that helped determine the cancers targeted for screening. In addition, Maryland funded local minority outreach and technical assistance (MOTA) programs to ensure the participation of racial/ethnic minority groups in the CRF cancer and tobacco programs in the 17 jurisdictions with the highest percentage of minority residents. Because screening for CRC was recommended but underutilized,<sup>6,12</sup> 23 jurisdictions initially targeted CRC; Baltimore City chose other cancers for its screening program.

We report on the first eight years of this nearly statewide program and evaluate the feasibility, outcomes,

and lessons learned from CRC screening targeting low-income, uninsured, medically underserved, and minority adults.

## METHODS

### Program development

The MDHMH convened a CRC Medical Advisory Committee, comprising a medical oncologist, three gastroenterologists, a pathologist, a radiation oncologist, and two primary care providers, to formulate medical guidelines for the program. The guidelines were based on national guidelines<sup>3,13</sup> and stated that local programs should offer CRC screening either by colonoscopy or by FOBT with flexible sigmoidoscopy to clients who met income and health insurance eligibility requirements. Some programs also offered FOBT screening without endoscopy to clients who did not meet income or insurance eligibility requirements for endoscopy; however, programs instructed these clients to see their doctor and complete their screening with either sigmoidoscopy or colonoscopy. DCBE was an alternative but was not chosen by providers as a first-line screening test. Each LHD decided on the screening method(s), income eligibility requirements (a maximum of 250% of the federal poverty level [FPL]), and whether to accept clients with gastrointestinal (GI) symptoms or a history of neoplasia.

The MDHMH awarded CRF funding to each LHD;<sup>11</sup> managed local grants; provided clinical, technical, and administrative guidance; developed a clinical and management database; and distributed CRC fact sheets, consent forms, and templates of medical provider contracts. To provide outreach and education about screening opportunities to the public and providers, LHDs hired staff or contracted with other organizations and partnered with local MOTA programs. Emphasis was placed on outreach to minority and medically underserved adults.

LHDs hired clinical case-management staff and signed contracts with private doctors, endoscopy facilities, laboratories, and hospitals for physical exams, sigmoidoscopy, colonoscopy, DCBE, pathology, and other clinical services. Contracts required providers to follow the CRC state guidelines and accept Medicare rates for reimbursement of screening procedures (including colonoscopy and biopsy). For half of the jurisdictions that had sufficient funds to pay for diagnosis (beyond colonoscopy and biopsy) or treatment when cancer was detected, diagnosis and treatment services were paid at Medicaid rates. Programs without sufficient funds for treatment linked clients to treatment by helping with

Medicaid applications or by helping arrange hospital charity care, uncompensated care, and payment plans.

### Client enrollment, consent, and case management

Local programs recruited eligible clients through outreach to existing LHD clients (e.g., federally funded breast and cervical cancer screening clients and their male partners) at LHD clinics (e.g., influenza vaccination clinics); through referral from primary care providers, colonoscopists, or MOTA programs; at community sites or events (e.g., churches and health fairs); and through the media (e.g., television, radio, print media, and flyers).

Each client screened with only FOBT signed a consent form that acknowledged the limitations of the FOBT and the need for additional visualization of the colon to complete the screening. Each client who was screened with FOBT, sigmoidoscopy, colonoscopy, or DCBE signed a consent form acknowledging that the screening data would be shared with MDHMH and its data contractor to be used for quality assurance and program evaluation. In those LHDs not covering diagnosis and treatment costs, consent acknowledged that the program would link to care but would not cover these costs if further tests or treatments were needed. Medical providers ordered bowel preparation and obtained clinical consent for the procedures performed. Either providers or program staff explained bowel preparation to clients.

The MDHMH established case-management guidelines for appropriate follow-up and referral of clients based on the test(s) and results. Local case managers navigated the client through screening with reminders about appointments and bowel preparation, follow-up calls, and transportation; collected and entered data from patients and providers; notified clients of results; and recalled clients for their next CRC test. MDHMH oversaw the quality of clinical and case-management services of medical providers and the local program staff through data reviews and site visits.

### Data collection and analysis

MDHMH established standard data elements and forms. Data included self-reported demographic information, personal and family CRC risk factors, symptoms, and previous history of CRC screening. A client was considered at increased risk for CRC if he or she had a personal history of CRC, adenoma(s), or a polyp of unknown type, and/or a family history of CRC, adenoma(s), or a polyp of unknown type.<sup>14</sup> We included a history of polyp of unknown type in our definition of increased risk so we would not miss those

who were at increased risk when the clients' pathology results were not known. A client was considered at average risk if he or she had no increased risk for CRC.

Screening procedure results, pathology results (if any), unplanned events or complications of the procedure(s), and treatment and staging of diagnosed cancers were recorded in the database. Programs accepted the providers' customary reports; providers were not required to complete additional standardized forms. Adverse events that occurred during the procedure and required termination of the procedure, or occurred within 30 days following endoscopy and required medical evaluation, were considered endoscopic complications.

Data were entered into the secure, confidential, intranet-based client database (CDB). For quality assurance, on clients with cancer or adenoma(s), MDHMH compared coded data in the CDB with the text of colonoscopy and pathology reports to assure the accuracy of data entry for lesion size and histology.

We analyzed data from the initial screening cycle for each client during the first eight years of the program. We categorized each screening into one of four categories based on the most advanced procedure the client had in the cycle using the following hierarchy (from most advanced to least advanced): colonoscopy (with or without FOBT or other procedures in the cycle), sigmoidoscopy (with or without FOBT and without colonoscopy), DCBE (with or without FOBT and without colonoscopy or sigmoidoscopy), or FOBT only.

Based on gross and histologic findings of all procedures in a cycle, a final diagnosis for the screening cycle was assigned as the most advanced finding of the following: colorectal adenocarcinoma, high-risk adenoma, low-risk adenoma, hyperplastic polyp, other finding, or "normal" colonoscopy (i.e., a colonoscopy without these findings). A high-risk adenoma was one with high-grade dysplasia, villous or tubulovillous histology,  $\geq 10$  millimeters (mm) in diameter, or noted as large on the colonoscopy report. A low-risk adenoma was one with tubular histology without a villous component and  $< 10$  mm in diameter. Other findings included hemorrhoids, diverticula, other non-neoplastic diagnoses (e.g., inflammatory bowel disease and lymphoid aggregates), and polyps that were noted on the colonoscopy report but either had no pathology results (i.e., those that were ablated or lost during retrieval or processing) or were noted as normal mucosa on pathology. In clients with more than one lesion, the final diagnosis and adenoma classification were based on the most advanced lesion. Anal and rectal squamous cell carcinomas, lymphoma,

and carcinoid tumors of the colon or rectum were categorized separately for this analysis.

We conducted the analysis using Microsoft® Excel and SAS® version 9.2.<sup>15</sup> We examined differences in client characteristics by screening test using Chi-square statistics.

## RESULTS

In 2000, colonoscopy was selected as the primary CRC screening method for those at average risk in four programs, FOBT with flexible sigmoidoscopy was selected as the primary CRC screening method in 18 programs, and FOBT alone was selected as the primary screening method in one program. Positive FOBTs were followed by colonoscopy in the program for those who were eligible; those who were not eligible were referred to their own providers. Figure 1 shows the distribution of CRC tests by year. By 2004, the primary CRC screening method became colonoscopy in 22 programs, and one program stopped CRC screening. Ten of the 22 programs additionally offered FOBT to those who were not eligible for colonoscopy in their program or to those who were eligible for but not yet willing to accept colonoscopy.

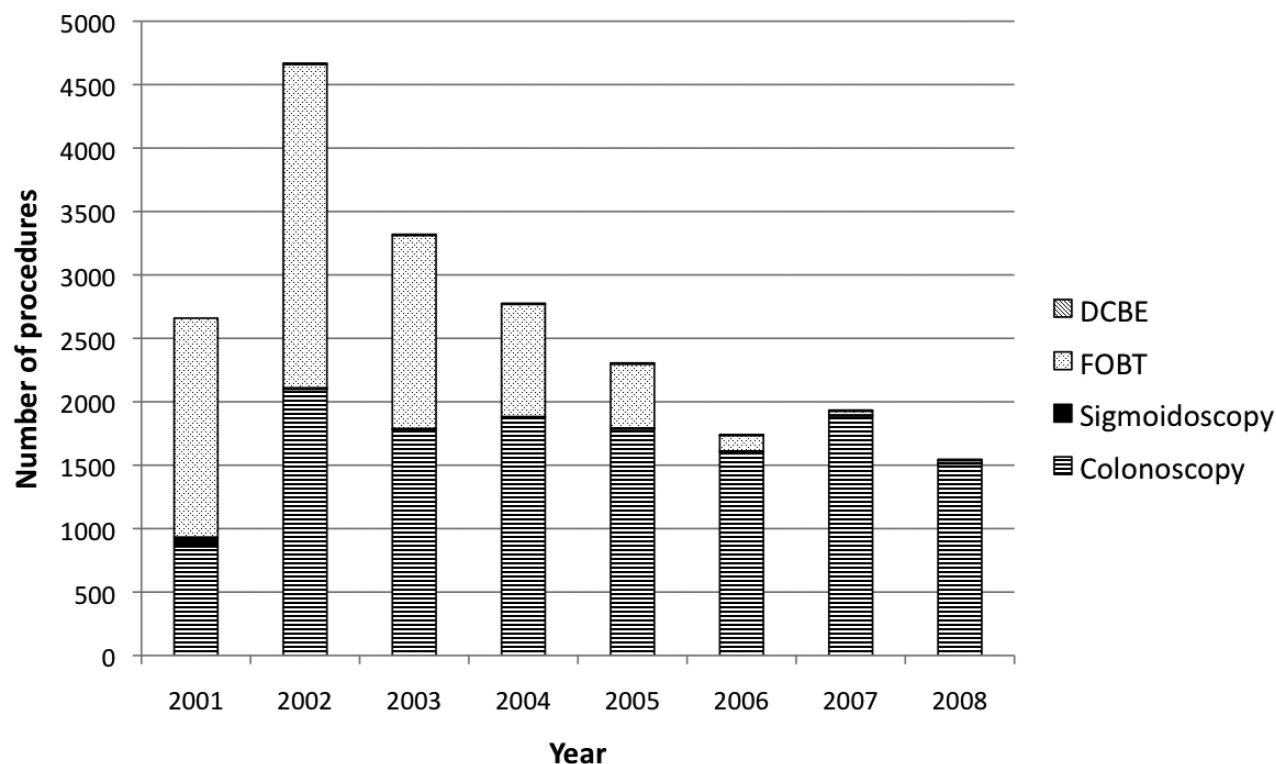
Programs contracted with 189 endoscopists statewide to perform colonoscopy, including individual gastroenterologists or gastroenterology practices ( $n=161$ ) and surgeons or surgical practices ( $n=28$ ). All 23 programs chose to enroll clients regardless of pre-enrollment CRC screening and results; 22 programs enrolled clients who reported GI symptoms, including GI bleeding.

From July 1, 2000, to December 31, 2008, the LHDs enrolled 17,065 clients. They recorded 20,951 screening cycles (17,065 first screening cycles and 3,886 subsequent cycles) and performed 13,588 colonoscopies, 155 sigmoidoscopies, 227 DCBEs, and 8,316 FOBT procedures.

The Table shows the demographics, risk history, and symptoms of the 17,065 clients categorized by the most advanced procedure that the individual had in his or her first cycle. Overall, 81.9% of the clients were aged 50 years or older, 68.6% were female, and 50.0% were of a racial/ethnic minority group. Those considered at increased risk for CRC accounted for 24.2% of the total, based on having a first-degree relative with CRC or adenoma (19.3%) and/or a personal history of CRC (0.7%), adenoma (3.7%), or unspecified type of polyp (3.0%). At enrollment, 68.5% reported no GI symptoms, 13.0% noted one or more episodes of rectal bleeding or blood in the stool (with or without other GI symptoms), and 18.5% reported GI symptoms without



**Figure 1. Number of colorectal cancer testing procedures, by year: Maryland Cigarette Restitution Fund program, 2000–2008**



DCBE = double-contrast barium enema

FOBT = fecal occult blood test

bleeding (i.e., lower abdominal pain, change in bowel habits, unexplained weight loss, or other symptoms). Of all clients screened, 53.9% were of average CRC risk without GI symptoms on enrollment to the first cycle. Colonoscopy was the most advanced procedure in 11,553 (67.7%) cycles, sigmoidoscopy in 86 (0.5%) cycles, DCBE in 17 (0.1%) cycles, and FOBT in 5,409 (31.7%) cycles.

Of the initial colonoscopies in the first cycle, 7.6% were considered inadequate by the endoscopist. Figure 2 shows the final diagnosis of the first cycle of screening by the most advanced procedure paid for by the program. In addition to the 107 adenocarcinomas (Figure 2), seven carcinoid tumors, one colonic lymphoma, two rectal squamous cell carcinomas, and three anal squamous cell carcinomas were identified in the first cycle (data not shown).

Of the 107 clients diagnosed with adenocarcinoma, two died of advanced disease without treatment; 55 had all or part of their treatment funded by the CRF program; and 50 were linked to treatment services paid

for by Medicaid, hospital charity care, or private funds. Ninety percent of the treated clients began their treatment within 60 days of diagnosis of cancer (diagnosis made at the time of colonoscopy or at the time of a subsequent procedure) (data not shown).

Staging was reported for 87 (81.3%) of the adenocarcinomas: 16 (15.0%) were Stage 1, 23 (21.5%) were Stage 2, 27 (25.2%) were Stage 3, and 21 (19.6%) were Stage 4. The LHD did not obtain the final stage of cancer following diagnosis for 20 (18.7%) cancer cases (data not shown).

Adverse events were reported in 91 of the 13,588 colonoscopies (0.7%); 23 (0.2%) were considered major. There were six bowel perforations, one of which was associated with biopsy of a lesion, one that was associated with fulguration of a polyp, two that were associated with diverticulosis, and two that were associated with difficulty advancing the colonoscope. One client had a stroke within 30 days of the colonoscopy. There were 16 major bleeding episodes, each occurring after biopsy or polypectomy, 11 requiring hospitalization

**Table. Demographic and colorectal cancer risk characteristics for 17,065 clients, by most advanced screening procedure in the first cycle: Maryland Cigarette Restitution Fund program, 2000–2008**

| Characteristic                            | Most advanced procedure in first cycle |                             |                           |                  |                     |
|-------------------------------------------|----------------------------------------|-----------------------------|---------------------------|------------------|---------------------|
|                                           | Total<br>(n = 17,065)                  | Colonoscopy<br>(n = 11,553) | Sigmoidoscopy<br>(n = 86) | DCBE<br>(n = 17) | FOBT<br>(n = 5,409) |
|                                           | N (percent)                            | N (percent)                 | N (percent)               | N (percent)      | N (percent)         |
| Age group (in years) <sup>a</sup>         |                                        |                             |                           |                  |                     |
| <50                                       | 3,017 (18.1)                           | 1,978 (17.1)                | 12 (14.0)                 | 4 (23.5)         | 1,023 (20.2)        |
| 50–54                                     | 4,311 (25.8)                           | 3,546 (30.7)                | 23 (26.7)                 | 3 (17.6)         | 739 (14.6)          |
| 55–59                                     | 3,451 (20.7)                           | 2,671 (23.1)                | 31 (36.0)                 | 2 (11.8)         | 747 (14.8)          |
| 60–64                                     | 3,329 (19.9)                           | 2,495 (21.6)                | 19 (22.1)                 | 4 (23.5)         | 811 (16.0)          |
| ≥65                                       | 2,601 (15.6)                           | 863 (7.5)                   | 1 (1.2)                   | 4 (23.5)         | 1,733 (34.3)        |
| Gender <sup>b</sup>                       |                                        |                             |                           |                  |                     |
| Female                                    | 11,691 (68.6)                          | 8,080 (69.9)                | 68 (79.1)                 | 12 (70.6)        | 3,531 (65.6)        |
| Male                                      | 5,344 (31.4)                           | 3,473 (30.1)                | 18 (20.9)                 | 5 (29.4)         | 1,848 (34.4)        |
| Race/ethnicity <sup>c</sup>               |                                        |                             |                           |                  |                     |
| Non-Hispanic white                        | 8,304 (50.0)                           | 5,408 (47.1)                | 35 (42.7)                 | 15 (88.2)        | 2,846 (56.5)        |
| Non-Hispanic black                        | 3,982 (24.0)                           | 3,067 (26.7)                | 32 (39.0)                 | 1 (5.9)          | 882 (17.5)          |
| Non-Hispanic other                        | 1,478 (8.9)                            | 998 (8.7)                   | 8 (9.8)                   | 1 (5.9)          | 471 (9.4)           |
| Hispanic any race                         | 2,849 (17.1)                           | 2,006 (17.5)                | 7 (8.5)                   | 0 (0.0)          | 836 (16.6)          |
| First-degree relative with CRC or adenoma | 3,290 (19.3)                           | 2,623 (22.7)                | 10 (11.6)                 | 4 (23.5)         | 653 (12.1)          |
| Previous history of CRC or adenoma        |                                        |                             |                           |                  |                     |
| History of CRC                            | 119 (0.7)                              | 97 (0.8)                    | 1 (1.2)                   | 0 (0.0)          | 21 (0.4)            |
| History of adenoma                        | 628 (3.7)                              | 413 (3.6)                   | 0 (0.0)                   | 2 (11.8)         | 213 (3.9)           |
| History of polyps, type unknown           | 510 (3.0)                              | 392 (3.4)                   | 0 (0.0)                   | 1 (5.9)          | 117 (2.2)           |
| Previous colonoscopy, no reported polyps  | 807 (4.7)                              | 620 (5.4)                   | 1 (1.2)                   | 1 (5.9)          | 185 (3.4)           |
| No previous colonoscopy                   | 15,001 (87.9)                          | 10,031 (86.8)               | 84 (97.7)                 | 13 (76.5)        | 4,873 (90.1)        |
| Previous history of FOBT                  |                                        |                             |                           |                  |                     |
| Yes                                       | 696 (4.1)                              | 657 (5.7)                   | 12 (14.0)                 | 0 (0.0)          | 12 (0.2)            |
| No                                        | 16,369 (95.9)                          | 10,896 (94.3)               | 74 (86.0)                 | 17 (100.0)       | 5,382 (99.5)        |
| Risk based on family and personal history |                                        |                             |                           |                  |                     |
| Average risk <sup>d</sup>                 | 12,934 (75.8)                          | 8,340 (72.2)                | 76 (88.4)                 | 10 (58.8)        | 4,508 (83.3)        |
| Increased risk <sup>d</sup>               | 4,131 (24.2)                           | 3,213 (27.8)                | 10 (11.6)                 | 7 (41.2)         | 901 (16.7)          |

continued on p. 335

**Table (continued). Demographic and colorectal cancer risk characteristics for 17,065 clients, by most advanced screening procedure in the first cycle: Maryland Cigarette Restitution Fund program, 2000–2008**

| Characteristic                                | Most advanced procedure in first cycle |                             |                           |                  |                     |
|-----------------------------------------------|----------------------------------------|-----------------------------|---------------------------|------------------|---------------------|
|                                               | Total<br>(n = 17,065)                  | Colonoscopy<br>(n = 11,553) | Sigmoidoscopy<br>(n = 86) | DCBE<br>(n = 17) | FOBT<br>(n = 5,409) |
|                                               | N (percent)                            | N (percent)                 | N (percent)               | N (percent)      | N (percent)         |
| Symptoms                                      |                                        |                             |                           |                  |                     |
| None                                          | 11,681 (68.5)                          | 6,871 (59.5)                | 57 (66.3)                 | 9 (52.9)         | 4,744 (87.7)        |
| GI bleeding with or without other GI symptoms | 2,225 (13.0)                           | 2,128 (18.4)                | 9 (10.5)                  | 1 (5.9)          | 87 (1.6)            |
| GI symptoms without bleeding                  | 3,159 (18.5)                           | 2,554 (22.1)                | 20 (23.3)                 | 7 (41.2)         | 578 (10.7)          |
| Risk and/or symptoms                          |                                        |                             |                           |                  |                     |
| Average risk, no/unknown symptoms             | 9,197 (53.9)                           | 5,131 (44.4)                | 50 (58.1)                 | 3 (17.6)         | 4,013 (74.2)        |
| Increased risk and/or symptoms                | 7,868 (46.1)                           | 6,422 (55.6)                | 36 (41.9)                 | 14 (82.4)        | 1,396 (25.8)        |

<sup>a</sup>Age was missing for 356 clients with FOBT.

<sup>b</sup>Gender was missing for 30 clients with FOBT.

<sup>c</sup>Race/ethnicity was missing for 74 clients with colonoscopy, four clients with sigmoidoscopy, and 374 clients with FOBT.

<sup>d</sup>Average risk was defined as all clients without increased risk of CRC. Increased risk was defined as a client with a personal history of CRC, adenoma(s), polyp of unknown type, and/or a family history of CRC, adenoma, or polyp of unknown type.

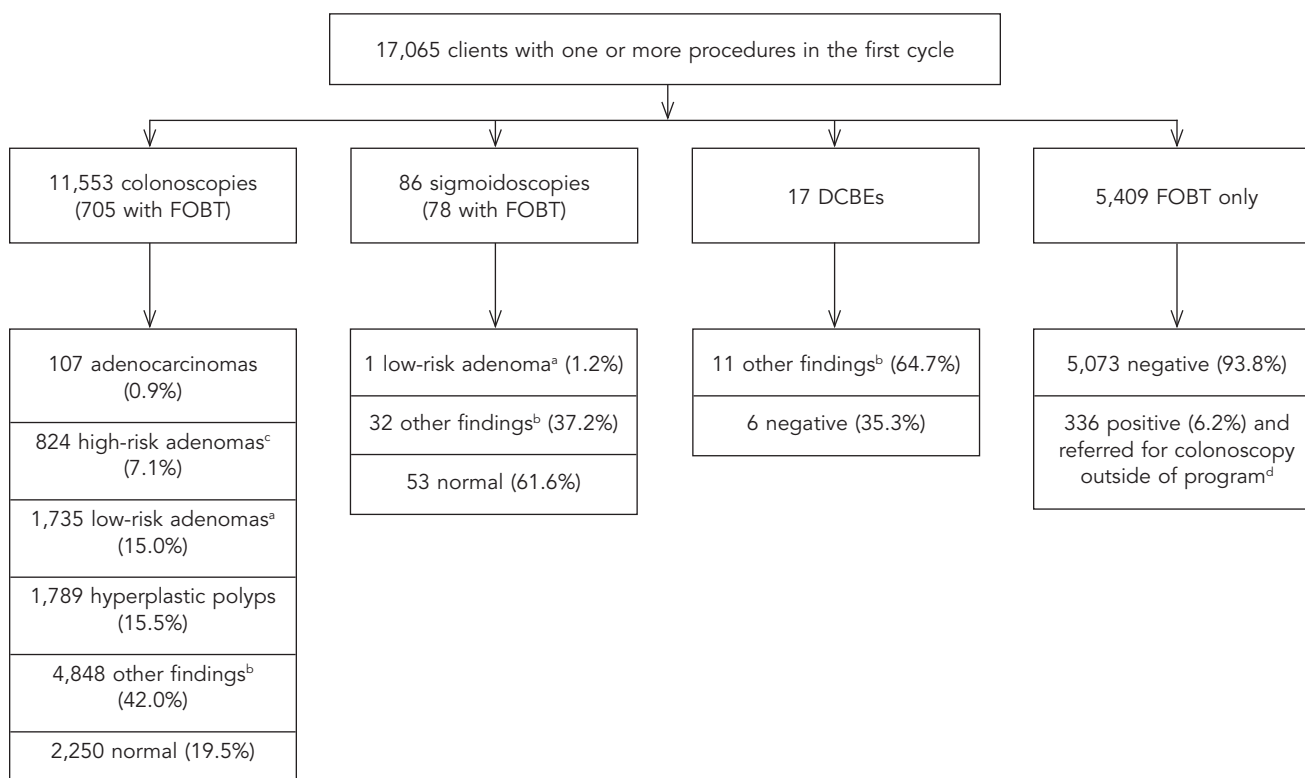
DCBE = double-contrast barium enema

FOBT = fecal occult blood test

CRC = colorectal cancer

GI = gastrointestinal

**Figure 2. Flow chart of clients by the most advanced testing procedure in the first colorectal cancer testing cycle and final diagnosis or test result: Maryland Cigarette Restitution Fund program, 2000–2008**



<sup>a</sup>Low-risk adenoma is a tubular histology without a villous component but <1 cm in size.

<sup>b</sup>Other findings included hemorrhoids, diverticula, inflammatory bowel disease, other non-neoplastic diagnoses, or polyps that were noted on the colonoscopy report but either had no pathology results (i.e., those that were ablated or lost during retrieval or processing) or were noted as normal mucosa on pathology.

<sup>c</sup>High-risk adenoma is an adenoma with high-grade dysplasia, villous component, or ≥1 cm in size.

<sup>d</sup>Results included cancer (n=6), adenomas (n=7), other findings (n=112), and referred but follow-up information not obtained (n=211).

FOBT = fecal occult blood test

DCBE = double-contrast barium enema

cm = centimeter

or surgery, and five requiring an emergency room visit. Minor complications included 68 events such as bleeding that did not require an emergency room visit, arrhythmia, hypo- or hypertension, intra- or post-procedure abdominal pain, nausea, vomiting, diarrhea, inability to sedate for the colonoscopy, or combativeness (data not shown).

## DISCUSSION

We report the development and results of a complex, ongoing public health CRC testing program that targets low-income, uninsured, and racial/ethnic minority adults. Funding from the CRF made it possible for

Maryland to implement a program that addressed many aspects foreseen in the National Colorectal Cancer Roundtable Strategic Plan.<sup>16</sup> More than 46% of our clients were at increased risk and/or reported some degree of GI symptoms, including those with family risk, a personal history of CRC, adenomas or polyps of unknown type, and GI symptoms that were not suggestive of CRC. While most of our clients received screening colonoscopies, some were surveillance colonoscopies, and a few were diagnostic colonoscopies. We have therefore referred to this program as a testing program.

During the first eight years, the program tested more than 17,000 clients. The program successfully

reached people in racial/ethnic minority groups: the percentage of clients enrolled who were aged 50 years and older and of a racial/ethnic minority group was more than twice the percentage of those residing in the counties with the CRC screening program (51% vs. 24%). The program was very effective in reaching this underserved population in Maryland: of the 13,692 clients aged 50 years and older at enrollment, 14% reported being previously tested with a colonoscopy or sigmoidoscopy compared with 63% of adults aged 50 years and older in the Maryland population in 2004.<sup>17</sup> Based on 2004 estimates, there were 73,618 Marylanders aged 50–64 years who were uninsured,<sup>18</sup> approximately 12% of whom received a colonoscopy in our program during 2000–2008.

If roughly 40% of high-risk adenomas progress to cancer,<sup>19,20</sup> we estimate this program may have prevented at least 300 cases of CRC through polypectomy. The rate of major complications in our program falls within the rates cited for the systematic review of the USPSTF, released in 2008.<sup>21</sup>

Maryland's 23 local programs received guidance, administrative oversight, and funding from the MDHMH,<sup>22</sup> but each was designed and administered locally. Local providers, hospitals, community groups, and clients in communities with and without racial/ethnic minority groups embraced this successful public-private partnership as a benefit to their communities.

Rather than excluding participants because of increased risk, prior screening, or symptoms, the local

programs enrolled clients representing a cross-section of risk, symptoms, and prior medical and CRC screening histories. Despite broadening our eligibility and serving more clients in need, our cancer and adenoma detection rates are comparable with U.S. studies cited in a meta-analysis of screening colonoscopies in asymptomatic people.<sup>23</sup> We compared the stages of CRC diagnosed in the program with stages of CRC reported in Maryland from 2001 to 2008. The proportion of cancers with known stage in the CRF program that were at the local stage (Stage 1) was 18.4% compared with 40.5% for the state; 57.5% in the CRF program were at the regional stage (25.2% Stage 2 and 19.6% Stage 3) vs. 39.5% for the state; and 24.1% in the CRF program were at the distant stage (Stage 4) vs. 20.1% for the state.<sup>24</sup> Detecting later stages may reflect that we reached the underserved who otherwise might not have been reached for screening (especially with colonoscopy).

MDHMH staff assured standardization and quality by developing and monitoring standardized clinical guidelines including recall intervals based on findings (Figure 3) and standardized data elements in colonoscopy reports. The MDHMH oversaw the local programs through frequent communication; routine quality review of results and recall intervals in the client database; and annual on-site program reviews, including individual chart reviews and review of colonoscopy and pathology reports. These reviews provided feedback on whether the providers' management and

**Figure 3. Guidelines for the interval to next colonoscopy based on findings of colonoscopy<sup>a</sup> per colorectal cancer minimal elements: Maryland Department of Health and Mental Hygiene, March 2009**

| <i>Colonoscopy findings</i>                                                                                                                                                           | <i>Interval to next colonoscopy<sup>a</sup></i>                                                                                                                                                |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| >10 adenomas of any size                                                                                                                                                              | Colonoscopy at <3 years; interval based on clinical judgment                                                                                                                                   |
| ≥1 large (≥1 cm) adenoma; 3–10 adenomas of any size or histology; ≥1 adenoma of any size with villous or tubulovillous histology, serrated adenoma histology, or high-grade dysplasia | Colonoscopy in three years after initial polyp removal                                                                                                                                         |
| 1–2 small (<1 cm) tubular adenomas with no villous histology and no high-grade dysplasia                                                                                              | Colonoscopy in 5–10 years after initial polyp removal. Interval to be based on other factors, such as family history, prior colonoscopy findings, physician judgment, and patient preferences. |
| Multiple or large hyperplastic polyps suggestive of hyperplastic polyposis syndrome                                                                                                   | Colonoscopy every 6–12 months. These clients are best referred to a center with experience managing this syndrome.                                                                             |
| Small number of rectal hyperplastic polyps                                                                                                                                            | Colonoscopy in 10 years <sup>b</sup>                                                                                                                                                           |
| Normal colonoscopy                                                                                                                                                                    | Colonoscopy in 10 years <sup>b</sup>                                                                                                                                                           |

<sup>a</sup>Interval is based on colonoscopy being complete (i.e., the bowel preparation was adequate and cecum was reached) and neoplastic lesions being completely removed. If not, repeat colonoscopies should be performed at very short intervals (0–6 months).

<sup>b</sup>Interval should take family history into account. Patients with family history of colorectal cancer or adenomatous polyps in a first-degree relative (FDR) aged <60 years or ≥2 FDRs at any age should consider repeat colonoscopy within 5–10 years.

cm = centimeter



recall intervals agreed with program guidelines, and whether the local programs had accurately entered data in the CDB and managed cases appropriately.

The CRC testing methods changed over time: by 2006, 22 of 23 programs selected colonoscopy as the primary screening method (Figure 1). Factors that influenced this change included the time, expense, and difficulty of operating an annual FOBT-based screening program; the ease of case-managing clients who had no findings on colonoscopy and a 10-year recall; the inability of finding providers to perform sigmoidoscopy; the national shift toward colonoscopy as the most recommended CRC screening test;<sup>25,26</sup> and the ability of colonoscopy to both diagnose and treat some cancers as well as prevent cancer through polypectomy.

Programs additionally found it difficult to limit FOBT distribution to asymptomatic people of average risk. Hoping to reach the largest number of people with a low-cost screening test, several programs offered FOBT kits at health fairs and community events in the program's early years. Of those who took kits, more than 20% of those screened only with an FOBT in their first cycle were younger than 50 years of age (and not eligible for average risk screening) and more than 25% reported some GI symptom or risk and should have received a colonoscopy rather than an FOBT, according to program guidelines. Also, some jurisdictions initially found that starting CRC screening with an FOBT was more acceptable to clients who were not yet ready for endoscopy. Those with positive FOBTs who were ineligible for colonoscopy in the program due to income or insurance were notified of results and referred for colonoscopy; however, follow-up information on these clients was often difficult to obtain.

The income limit for eligibility increased over time in many jurisdictions. Programs found it difficult to recruit clients who had incomes  $\leq 100\%$  FPL. Clients with income eligibility matching that of the federal breast and cervical cancer program in Maryland (250% FPL) were easier to locate and recruit.

Recruitment and outreach efforts included linkages with medical clinics serving low-income/uninsured patients, physician offices, outreach to low-income workers at their worksites, hair salon/barber shop outreach, flyers in Laundromats and restrooms, and door-to-door outreach in low-income and minority neighborhoods. Despite these efforts, it was more difficult to recruit men than women. The percentage of men in the screening program has increased to only 36% in the last two years of the program despite outreach efforts (data not shown).

LHD staff remained integrally involved in their

clients' care after the diagnosis of cancer was made, whether or not treatment was funded by the CRF program. Anecdotally, counties that linked their clients to other payment methods for treatment invested a significant amount of time helping clients complete and submit applications for Medicaid, hospital charity care, and other sources of funding in a timely manner.

Since its inception, the Maryland program has consulted with numerous other state programs and with the Centers for Disease Control and Prevention CRC Screening Demonstration Program,<sup>27,28</sup> which funded Baltimore City as a CRC screening demonstration site in 2005.

## CONCLUSIONS

The Maryland CRF program has successfully shown that low-income and underserved members of the community will take advantage of CRC screening. We have also shown that a program based predominantly on colonoscopy is challenging but feasible. It is acceptable to clients and providers, and it is associated with good outcomes for primary and secondary prevention of CRC. If health-care reform is enacted, many underserved clients will gain access to CRC screening and other preventive services, but the public health roles of outreach, education, enrollment, and overcoming barriers through navigation will still be necessary to improve screening rates.

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The Institutional Review Board (IRB) of the MDHMH exempted this program evaluation project, and the UM IRB approved the project.

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# Local Acts

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Disparities in cancer occurrence and cancer outcomes are caused by the disproportionate accrual of risks among racial/ethnic minority, low-income, and uninsured groups across the prevention, detection, and treatment spectrum. Reducing cancer disparities requires efforts in each arena. This article describes one local initiative to improve screening and detection rates among uninsured, low-income, and minority older adults living in Maryland using funding from the Cigarette Restitution Fund. The authors present useful findings on screening volume and results to characterize the impact of the program, indicating that, in addition to the 120 cancers identified, as many as 300 colorectal cancers may have been prevented by polypectomy in the program.

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## EXPERIENCE OF A PUBLIC HEALTH COLORECTAL CANCER TESTING PROGRAM IN MARYLAND

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Colorectal cancer (CRC) was the second leading cause of cancer death among men and women nationally and in Maryland in 2000.<sup>1,2</sup> African Americans in Maryland had an age-adjusted CRC mortality rate that was 1.4 times that of white people (31.1 per 100,000 population vs. 22.1 per 100,000 population for black and white people, respectively).<sup>2</sup> American Cancer Society (ACS) recommendations for CRC screening published in 1997 provided a menu of screening options.<sup>3</sup> Of these, fecal occult blood test (FOBT) and sigmoidoscopy screening have been covered under Medicare Part B since 1998. In 2001, Medicare Part B initiated coverage for colonoscopy screening.<sup>4</sup> In 1999, only 29.1% of Marylanders aged 50–64 years reported having an FOBT in the last year, and only 41.2% had a sigmoidoscopy or colonoscopy within the previous five years.<sup>5</sup> Screening disparities existed with lower screening rates in individuals with lower income, without health insurance, and of minority race/ethnicity.<sup>6</sup>

Although CRC screening has been shown to reduce mortality,<sup>7,8</sup> prior to 2000, only New York State had initiated a public health screening program that used FOBT for screening its low-income uninsured popula-

tion.<sup>9</sup> In 2002, the U.S. Preventive Services Task Force (USPSTF) recommended CRC screening for those aged 50 years and older.<sup>10</sup> Tests and intervals had been further defined by the ACS, and screening test options for those at average risk included (1) annual FOBT, (2) flexible sigmoidoscopy every five years, (3) annual FOBT with flexible sigmoidoscopy every five years, (4) double-contrast barium enema (DCBE) every five years, or (5) colonoscopy every 10 years. While FOBT may detect bleeding from some larger, advanced adenomas and CRCs, non-bleeding lesions can only be found and removed during sigmoidoscopy and colonoscopy. For those at increased risk of CRC or with symptoms, colonoscopy is recommended.

Following the multistate Master Tobacco Settlement Agreement, Maryland established the Cigarette Restitution Fund (CRF) in 2000.<sup>11</sup> The goal of the CRF is to decrease cancer mortality and reduce racial/ethnic disparities in cancer mortality. The Maryland Department of Health and Mental Hygiene (MDHMH) initially developed and now supervises a statewide cancer-control program administered by its local health departments (LHDs). Under the CRF law, each of Maryland's 24 LHDs formed a community health coalition that helped determine the cancers targeted for screening. In addition, Maryland funded local minority outreach and technical assistance (MOTA) programs to ensure the participation of racial/ethnic minority groups in the CRF cancer and tobacco programs in the 17 jurisdictions with the highest percentage of minority residents. Because screening for CRC was recommended but underutilized,<sup>6,12</sup> 23 jurisdictions initially targeted CRC; Baltimore City chose other cancers for its screening program.

We report on the first eight years of this nearly statewide program and evaluate the feasibility, outcomes,

and lessons learned from CRC screening targeting low-income, uninsured, medically underserved, and minority adults.

## METHODS

### Program development

The MDHMH convened a CRC Medical Advisory Committee, comprising a medical oncologist, three gastroenterologists, a pathologist, a radiation oncologist, and two primary care providers, to formulate medical guidelines for the program. The guidelines were based on national guidelines<sup>3,13</sup> and stated that local programs should offer CRC screening either by colonoscopy or by FOBT with flexible sigmoidoscopy to clients who met income and health insurance eligibility requirements. Some programs also offered FOBT screening without endoscopy to clients who did not meet income or insurance eligibility requirements for endoscopy; however, programs instructed these clients to see their doctor and complete their screening with either sigmoidoscopy or colonoscopy. DCBE was an alternative but was not chosen by providers as a first-line screening test. Each LHD decided on the screening method(s), income eligibility requirements (a maximum of 250% of the federal poverty level [FPL]), and whether to accept clients with gastrointestinal (GI) symptoms or a history of neoplasia.

The MDHMH awarded CRF funding to each LHD;<sup>11</sup> managed local grants; provided clinical, technical, and administrative guidance; developed a clinical and management database; and distributed CRC fact sheets, consent forms, and templates of medical provider contracts. To provide outreach and education about screening opportunities to the public and providers, LHDs hired staff or contracted with other organizations and partnered with local MOTA programs. Emphasis was placed on outreach to minority and medically underserved adults.

LHDs hired clinical case-management staff and signed contracts with private doctors, endoscopy facilities, laboratories, and hospitals for physical exams, sigmoidoscopy, colonoscopy, DCBE, pathology, and other clinical services. Contracts required providers to follow the CRC state guidelines and accept Medicare rates for reimbursement of screening procedures (including colonoscopy and biopsy). For half of the jurisdictions that had sufficient funds to pay for diagnosis (beyond colonoscopy and biopsy) or treatment when cancer was detected, diagnosis and treatment services were paid at Medicaid rates. Programs without sufficient funds for treatment linked clients to treatment by helping with

Medicaid applications or by helping arrange hospital charity care, uncompensated care, and payment plans.

### Client enrollment, consent, and case management

Local programs recruited eligible clients through outreach to existing LHD clients (e.g., federally funded breast and cervical cancer screening clients and their male partners) at LHD clinics (e.g., influenza vaccination clinics); through referral from primary care providers, colonoscopists, or MOTA programs; at community sites or events (e.g., churches and health fairs); and through the media (e.g., television, radio, print media, and flyers).

Each client screened with only FOBT signed a consent form that acknowledged the limitations of the FOBT and the need for additional visualization of the colon to complete the screening. Each client who was screened with FOBT, sigmoidoscopy, colonoscopy, or DCBE signed a consent form acknowledging that the screening data would be shared with MDHMH and its data contractor to be used for quality assurance and program evaluation. In those LHDs not covering diagnosis and treatment costs, consent acknowledged that the program would link to care but would not cover these costs if further tests or treatments were needed. Medical providers ordered bowel preparation and obtained clinical consent for the procedures performed. Either providers or program staff explained bowel preparation to clients.

The MDHMH established case-management guidelines for appropriate follow-up and referral of clients based on the test(s) and results. Local case managers navigated the client through screening with reminders about appointments and bowel preparation, follow-up calls, and transportation; collected and entered data from patients and providers; notified clients of results; and recalled clients for their next CRC test. MDHMH oversaw the quality of clinical and case-management services of medical providers and the local program staff through data reviews and site visits.

### Data collection and analysis

MDHMH established standard data elements and forms. Data included self-reported demographic information, personal and family CRC risk factors, symptoms, and previous history of CRC screening. A client was considered at increased risk for CRC if he or she had a personal history of CRC, adenoma(s), or a polyp of unknown type, and/or a family history of CRC, adenoma(s), or a polyp of unknown type.<sup>14</sup> We included a history of polyp of unknown type in our definition of increased risk so we would not miss those



who were at increased risk when the clients' pathology results were not known. A client was considered at average risk if he or she had no increased risk for CRC.

Screening procedure results, pathology results (if any), unplanned events or complications of the procedure(s), and treatment and staging of diagnosed cancers were recorded in the database. Programs accepted the providers' customary reports; providers were not required to complete additional standardized forms. Adverse events that occurred during the procedure and required termination of the procedure, or occurred within 30 days following endoscopy and required medical evaluation, were considered endoscopic complications.

Data were entered into the secure, confidential, intranet-based client database (CDB). For quality assurance, on clients with cancer or adenoma(s), MDHMH compared coded data in the CDB with the text of colonoscopy and pathology reports to assure the accuracy of data entry for lesion size and histology.

We analyzed data from the initial screening cycle for each client during the first eight years of the program. We categorized each screening into one of four categories based on the most advanced procedure the client had in the cycle using the following hierarchy (from most advanced to least advanced): colonoscopy (with or without FOBT or other procedures in the cycle), sigmoidoscopy (with or without FOBT and without colonoscopy), DCBE (with or without FOBT and without colonoscopy or sigmoidoscopy), or FOBT only.

Based on gross and histologic findings of all procedures in a cycle, a final diagnosis for the screening cycle was assigned as the most advanced finding of the following: colorectal adenocarcinoma, high-risk adenoma, low-risk adenoma, hyperplastic polyp, other finding, or "normal" colonoscopy (i.e., a colonoscopy without these findings). A high-risk adenoma was one with high-grade dysplasia, villous or tubulovillous histology,  $\geq 10$  millimeters (mm) in diameter, or noted as large on the colonoscopy report. A low-risk adenoma was one with tubular histology without a villous component and  $< 10$  mm in diameter. Other findings included hemorrhoids, diverticula, other non-neoplastic diagnoses (e.g., inflammatory bowel disease and lymphoid aggregates), and polyps that were noted on the colonoscopy report but either had no pathology results (i.e., those that were ablated or lost during retrieval or processing) or were noted as normal mucosa on pathology. In clients with more than one lesion, the final diagnosis and adenoma classification were based on the most advanced lesion. Anal and rectal squamous cell carcinomas, lymphoma,

and carcinoid tumors of the colon or rectum were categorized separately for this analysis.

We conducted the analysis using Microsoft® Excel and SAS® version 9.2.<sup>15</sup> We examined differences in client characteristics by screening test using Chi-square statistics.

## RESULTS

In 2000, colonoscopy was selected as the primary CRC screening method for those at average risk in four programs, FOBT with flexible sigmoidoscopy was selected as the primary CRC screening method in 18 programs, and FOBT alone was selected as the primary screening method in one program. Positive FOBTs were followed by colonoscopy in the program for those who were eligible; those who were not eligible were referred to their own providers. Figure 1 shows the distribution of CRC tests by year. By 2004, the primary CRC screening method became colonoscopy in 22 programs, and one program stopped CRC screening. Ten of the 22 programs additionally offered FOBT to those who were not eligible for colonoscopy in their program or to those who were eligible for but not yet willing to accept colonoscopy.

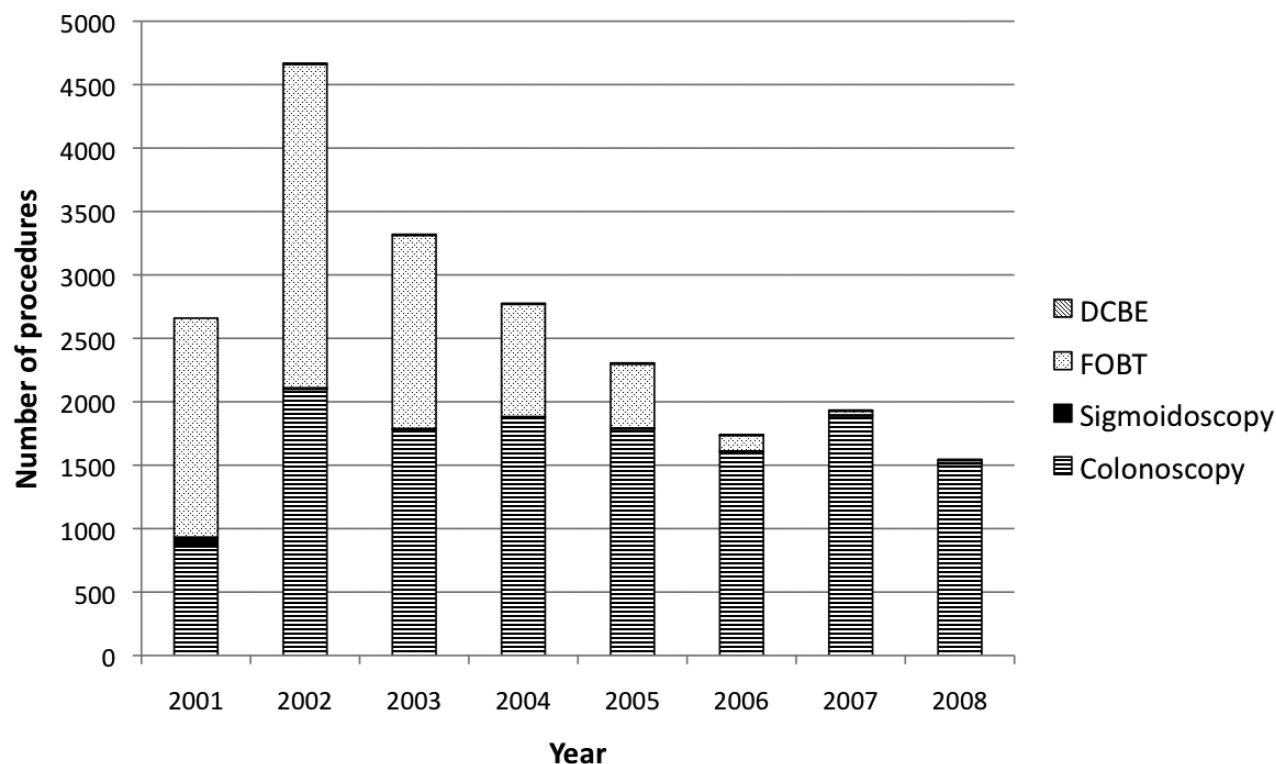
Programs contracted with 189 endoscopists statewide to perform colonoscopy, including individual gastroenterologists or gastroenterology practices ( $n=161$ ) and surgeons or surgical practices ( $n=28$ ). All 23 programs chose to enroll clients regardless of pre-enrollment CRC screening and results; 22 programs enrolled clients who reported GI symptoms, including GI bleeding.

From July 1, 2000, to December 31, 2008, the LHDs enrolled 17,065 clients. They recorded 20,951 screening cycles (17,065 first screening cycles and 3,886 subsequent cycles) and performed 13,588 colonoscopies, 155 sigmoidoscopies, 227 DCBEs, and 8,316 FOBT procedures.

The Table shows the demographics, risk history, and symptoms of the 17,065 clients categorized by the most advanced procedure that the individual had in his or her first cycle. Overall, 81.9% of the clients were aged 50 years or older, 68.6% were female, and 50.0% were of a racial/ethnic minority group. Those considered at increased risk for CRC accounted for 24.2% of the total, based on having a first-degree relative with CRC or adenoma (19.3%) and/or a personal history of CRC (0.7%), adenoma (3.7%), or unspecified type of polyp (3.0%). At enrollment, 68.5% reported no GI symptoms, 13.0% noted one or more episodes of rectal bleeding or blood in the stool (with or without other GI symptoms), and 18.5% reported GI symptoms without



**Figure 1. Number of colorectal cancer testing procedures, by year: Maryland Cigarette Restitution Fund program, 2000–2008**



DCBE = double-contrast barium enema

FOBT = fecal occult blood test

bleeding (i.e., lower abdominal pain, change in bowel habits, unexplained weight loss, or other symptoms). Of all clients screened, 53.9% were of average CRC risk without GI symptoms on enrollment to the first cycle. Colonoscopy was the most advanced procedure in 11,553 (67.7%) cycles, sigmoidoscopy in 86 (0.5%) cycles, DCBE in 17 (0.1%) cycles, and FOBT in 5,409 (31.7%) cycles.

Of the initial colonoscopies in the first cycle, 7.6% were considered inadequate by the endoscopist. Figure 2 shows the final diagnosis of the first cycle of screening by the most advanced procedure paid for by the program. In addition to the 107 adenocarcinomas (Figure 2), seven carcinoid tumors, one colonic lymphoma, two rectal squamous cell carcinomas, and three anal squamous cell carcinomas were identified in the first cycle (data not shown).

Of the 107 clients diagnosed with adenocarcinoma, two died of advanced disease without treatment; 55 had all or part of their treatment funded by the CRF program; and 50 were linked to treatment services paid

for by Medicaid, hospital charity care, or private funds. Ninety percent of the treated clients began their treatment within 60 days of diagnosis of cancer (diagnosis made at the time of colonoscopy or at the time of a subsequent procedure) (data not shown).

Staging was reported for 87 (81.3%) of the adenocarcinomas: 16 (15.0%) were Stage 1, 23 (21.5%) were Stage 2, 27 (25.2%) were Stage 3, and 21 (19.6%) were Stage 4. The LHD did not obtain the final stage of cancer following diagnosis for 20 (18.7%) cancer cases (data not shown).

Adverse events were reported in 91 of the 13,588 colonoscopies (0.7%); 23 (0.2%) were considered major. There were six bowel perforations, one of which was associated with biopsy of a lesion, one that was associated with fulguration of a polyp, two that were associated with diverticulosis, and two that were associated with difficulty advancing the colonoscope. One client had a stroke within 30 days of the colonoscopy. There were 16 major bleeding episodes, each occurring after biopsy or polypectomy, 11 requiring hospitalization

**Table. Demographic and colorectal cancer risk characteristics for 17,065 clients, by most advanced screening procedure in the first cycle: Maryland Cigarette Restitution Fund program, 2000–2008**

| Characteristic                            | Most advanced procedure in first cycle |                             |                           |                  |                     |
|-------------------------------------------|----------------------------------------|-----------------------------|---------------------------|------------------|---------------------|
|                                           | Total<br>(n = 17,065)                  | Colonoscopy<br>(n = 11,553) | Sigmoidoscopy<br>(n = 86) | DCBE<br>(n = 17) | FOBT<br>(n = 5,409) |
|                                           | N (percent)                            | N (percent)                 | N (percent)               | N (percent)      | N (percent)         |
| Age group (in years) <sup>a</sup>         |                                        |                             |                           |                  |                     |
| <50                                       | 3,017 (18.1)                           | 1,978 (17.1)                | 12 (14.0)                 | 4 (23.5)         | 1,023 (20.2)        |
| 50–54                                     | 4,311 (25.8)                           | 3,546 (30.7)                | 23 (26.7)                 | 3 (17.6)         | 739 (14.6)          |
| 55–59                                     | 3,451 (20.7)                           | 2,671 (23.1)                | 31 (36.0)                 | 2 (11.8)         | 747 (14.8)          |
| 60–64                                     | 3,329 (19.9)                           | 2,495 (21.6)                | 19 (22.1)                 | 4 (23.5)         | 811 (16.0)          |
| ≥65                                       | 2,601 (15.6)                           | 863 (7.5)                   | 1 (1.2)                   | 4 (23.5)         | 1,733 (34.3)        |
| Gender <sup>b</sup>                       |                                        |                             |                           |                  |                     |
| Female                                    | 11,691 (68.6)                          | 8,080 (69.9)                | 68 (79.1)                 | 12 (70.6)        | 3,531 (65.6)        |
| Male                                      | 5,344 (31.4)                           | 3,473 (30.1)                | 18 (20.9)                 | 5 (29.4)         | 1,848 (34.4)        |
| Race/ethnicity <sup>c</sup>               |                                        |                             |                           |                  |                     |
| Non-Hispanic white                        | 8,304 (50.0)                           | 5,408 (47.1)                | 35 (42.7)                 | 15 (88.2)        | 2,846 (56.5)        |
| Non-Hispanic black                        | 3,982 (24.0)                           | 3,067 (26.7)                | 32 (39.0)                 | 1 (5.9)          | 882 (17.5)          |
| Non-Hispanic other                        | 1,478 (8.9)                            | 998 (8.7)                   | 8 (9.8)                   | 1 (5.9)          | 471 (9.4)           |
| Hispanic any race                         | 2,849 (17.1)                           | 2,006 (17.5)                | 7 (8.5)                   | 0 (0.0)          | 836 (16.6)          |
| First-degree relative with CRC or adenoma | 3,290 (19.3)                           | 2,623 (22.7)                | 10 (11.6)                 | 4 (23.5)         | 653 (12.1)          |
| Previous history of CRC or adenoma        |                                        |                             |                           |                  |                     |
| History of CRC                            | 119 (0.7)                              | 97 (0.8)                    | 1 (1.2)                   | 0 (0.0)          | 21 (0.4)            |
| History of adenoma                        | 628 (3.7)                              | 413 (3.6)                   | 0 (0.0)                   | 2 (11.8)         | 213 (3.9)           |
| History of polyps, type unknown           | 510 (3.0)                              | 392 (3.4)                   | 0 (0.0)                   | 1 (5.9)          | 117 (2.2)           |
| Previous colonoscopy, no reported polyps  | 807 (4.7)                              | 620 (5.4)                   | 1 (1.2)                   | 1 (5.9)          | 185 (3.4)           |
| No previous colonoscopy                   | 15,001 (87.9)                          | 10,031 (86.8)               | 84 (97.7)                 | 13 (76.5)        | 4,873 (90.1)        |
| Previous history of FOBT                  |                                        |                             |                           |                  |                     |
| Yes                                       | 696 (4.1)                              | 657 (5.7)                   | 12 (14.0)                 | 0 (0.0)          | 12 (0.2)            |
| No                                        | 16,369 (95.9)                          | 10,896 (94.3)               | 74 (86.0)                 | 17 (100.0)       | 5,382 (99.5)        |
| Risk based on family and personal history |                                        |                             |                           |                  |                     |
| Average risk <sup>d</sup>                 | 12,934 (75.8)                          | 8,340 (72.2)                | 76 (88.4)                 | 10 (58.8)        | 4,508 (83.3)        |
| Increased risk <sup>d</sup>               | 4,131 (24.2)                           | 3,213 (27.8)                | 10 (11.6)                 | 7 (41.2)         | 901 (16.7)          |

continued on p. 335

**Table (continued). Demographic and colorectal cancer risk characteristics for 17,065 clients, by most advanced screening procedure in the first cycle: Maryland Cigarette Restitution Fund program, 2000–2008**

| Characteristic                                | Most advanced procedure in first cycle |                             |                           |                  |                     |
|-----------------------------------------------|----------------------------------------|-----------------------------|---------------------------|------------------|---------------------|
|                                               | Total<br>(n = 17,065)                  | Colonoscopy<br>(n = 11,553) | Sigmoidoscopy<br>(n = 86) | DCBE<br>(n = 17) | FOBT<br>(n = 5,409) |
|                                               | N (percent)                            | N (percent)                 | N (percent)               | N (percent)      | N (percent)         |
| Symptoms                                      |                                        |                             |                           |                  |                     |
| None                                          | 11,681 (68.5)                          | 6,871 (59.5)                | 57 (66.3)                 | 9 (52.9)         | 4,744 (87.7)        |
| GI bleeding with or without other GI symptoms | 2,225 (13.0)                           | 2,128 (18.4)                | 9 (10.5)                  | 1 (5.9)          | 87 (1.6)            |
| GI symptoms without bleeding                  | 3,159 (18.5)                           | 2,554 (22.1)                | 20 (23.3)                 | 7 (41.2)         | 578 (10.7)          |
| Risk and/or symptoms                          |                                        |                             |                           |                  |                     |
| Average risk, no/unknown symptoms             | 9,197 (53.9)                           | 5,131 (44.4)                | 50 (58.1)                 | 3 (17.6)         | 4,013 (74.2)        |
| Increased risk and/or symptoms                | 7,868 (46.1)                           | 6,422 (55.6)                | 36 (41.9)                 | 14 (82.4)        | 1,396 (25.8)        |

<sup>a</sup>Age was missing for 356 clients with FOBT.

<sup>b</sup>Gender was missing for 30 clients with FOBT.

<sup>c</sup>Race/ethnicity was missing for 74 clients with colonoscopy, four clients with sigmoidoscopy, and 374 clients with FOBT.

<sup>d</sup>Average risk was defined as all clients without increased risk of CRC. Increased risk was defined as a client with a personal history of CRC, adenoma(s), polyp of unknown type, and/or a family history of CRC, adenoma, or polyp of unknown type.

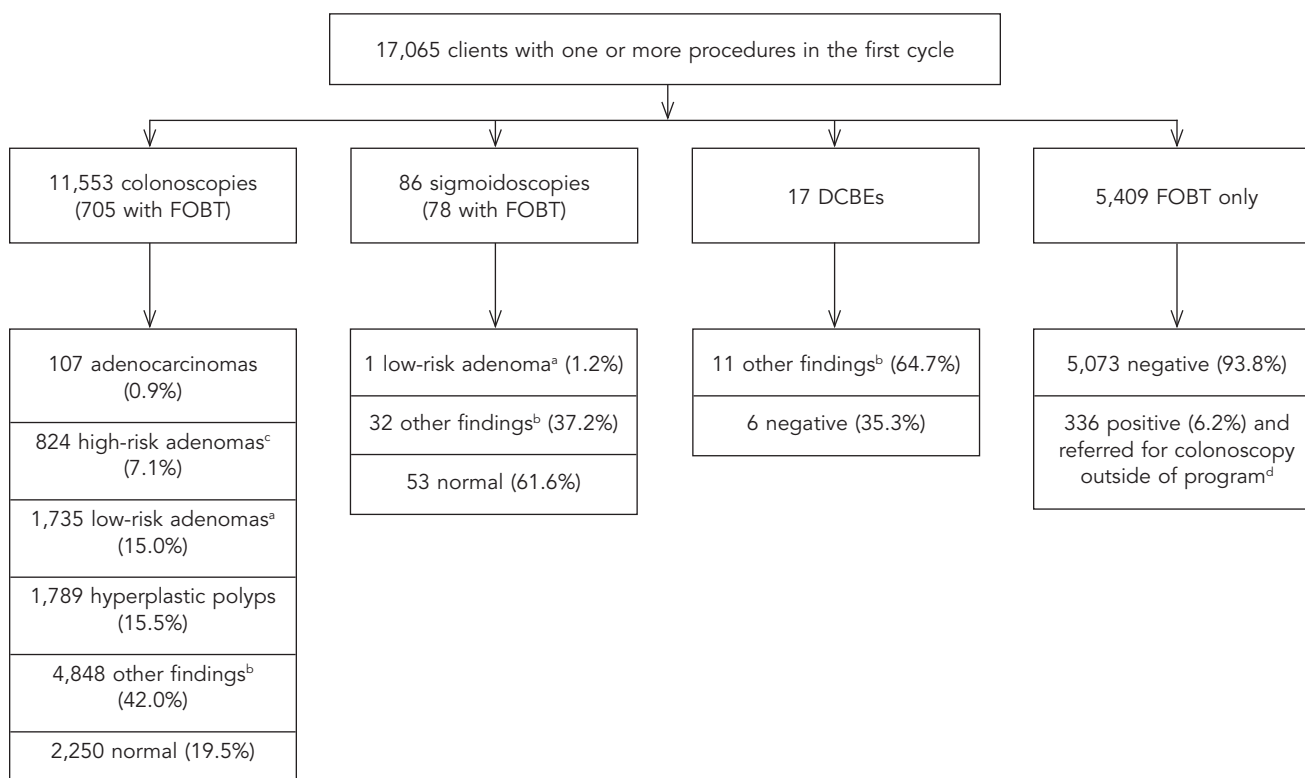
DCBE = double-contrast barium enema

FOBT = fecal occult blood test

CRC = colorectal cancer

GI = gastrointestinal

**Figure 2. Flow chart of clients by the most advanced testing procedure in the first colorectal cancer testing cycle and final diagnosis or test result: Maryland Cigarette Restitution Fund program, 2000–2008**



<sup>a</sup>Low-risk adenoma is a tubular histology without a villous component but <1 cm in size.

<sup>b</sup>Other findings included hemorrhoids, diverticula, inflammatory bowel disease, other non-neoplastic diagnoses, or polyps that were noted on the colonoscopy report but either had no pathology results (i.e., those that were ablated or lost during retrieval or processing) or were noted as normal mucosa on pathology.

<sup>c</sup>High-risk adenoma is an adenoma with high-grade dysplasia, villous component, or  $\geq 1$  cm in size.

<sup>d</sup>Results included cancer ( $n=6$ ), adenomas ( $n=7$ ), other findings ( $n=112$ ), and referred but follow-up information not obtained ( $n=211$ ).

FOBT = fecal occult blood test

DCBE = double-contrast barium enema

cm = centimeter

or surgery, and five requiring an emergency room visit. Minor complications included 68 events such as bleeding that did not require an emergency room visit, arrhythmia, hypo- or hypertension, intra- or post-procedure abdominal pain, nausea, vomiting, diarrhea, inability to sedate for the colonoscopy, or combativeness (data not shown).

## DISCUSSION

We report the development and results of a complex, ongoing public health CRC testing program that targets low-income, uninsured, and racial/ethnic minority adults. Funding from the CRF made it possible for

Maryland to implement a program that addressed many aspects foreseen in the National Colorectal Cancer Roundtable Strategic Plan.<sup>16</sup> More than 46% of our clients were at increased risk and/or reported some degree of GI symptoms, including those with family risk, a personal history of CRC, adenomas or polyps of unknown type, and GI symptoms that were not suggestive of CRC. While most of our clients received screening colonoscopies, some were surveillance colonoscopies, and a few were diagnostic colonoscopies. We have therefore referred to this program as a testing program.

During the first eight years, the program tested more than 17,000 clients. The program successfully

reached people in racial/ethnic minority groups: the percentage of clients enrolled who were aged 50 years and older and of a racial/ethnic minority group was more than twice the percentage of those residing in the counties with the CRC screening program (51% vs. 24%). The program was very effective in reaching this underserved population in Maryland: of the 13,692 clients aged 50 years and older at enrollment, 14% reported being previously tested with a colonoscopy or sigmoidoscopy compared with 63% of adults aged 50 years and older in the Maryland population in 2004.<sup>17</sup> Based on 2004 estimates, there were 73,618 Marylanders aged 50–64 years who were uninsured,<sup>18</sup> approximately 12% of whom received a colonoscopy in our program during 2000–2008.

If roughly 40% of high-risk adenomas progress to cancer,<sup>19,20</sup> we estimate this program may have prevented at least 300 cases of CRC through polypectomy. The rate of major complications in our program falls within the rates cited for the systematic review of the USPSTF, released in 2008.<sup>21</sup>

Maryland's 23 local programs received guidance, administrative oversight, and funding from the MDHMH,<sup>22</sup> but each was designed and administered locally. Local providers, hospitals, community groups, and clients in communities with and without racial/ethnic minority groups embraced this successful public-private partnership as a benefit to their communities.

Rather than excluding participants because of increased risk, prior screening, or symptoms, the local

programs enrolled clients representing a cross-section of risk, symptoms, and prior medical and CRC screening histories. Despite broadening our eligibility and serving more clients in need, our cancer and adenoma detection rates are comparable with U.S. studies cited in a meta-analysis of screening colonoscopies in asymptomatic people.<sup>23</sup> We compared the stages of CRC diagnosed in the program with stages of CRC reported in Maryland from 2001 to 2008. The proportion of cancers with known stage in the CRF program that were at the local stage (Stage 1) was 18.4% compared with 40.5% for the state; 57.5% in the CRF program were at the regional stage (25.2% Stage 2 and 19.6% Stage 3) vs. 39.5% for the state; and 24.1% in the CRF program were at the distant stage (Stage 4) vs. 20.1% for the state.<sup>24</sup> Detecting later stages may reflect that we reached the underserved who otherwise might not have been reached for screening (especially with colonoscopy).

MDHMH staff assured standardization and quality by developing and monitoring standardized clinical guidelines including recall intervals based on findings (Figure 3) and standardized data elements in colonoscopy reports. The MDHMH oversaw the local programs through frequent communication; routine quality review of results and recall intervals in the client database; and annual on-site program reviews, including individual chart reviews and review of colonoscopy and pathology reports. These reviews provided feedback on whether the providers' management and

**Figure 3. Guidelines for the interval to next colonoscopy based on findings of colonoscopy<sup>a</sup> per colorectal cancer minimal elements: Maryland Department of Health and Mental Hygiene, March 2009**

| <i>Colonoscopy findings</i>                                                                                                                                                           | <i>Interval to next colonoscopy<sup>a</sup></i>                                                                                                                                                |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| >10 adenomas of any size                                                                                                                                                              | Colonoscopy at <3 years; interval based on clinical judgment                                                                                                                                   |
| ≥1 large (≥1 cm) adenoma; 3–10 adenomas of any size or histology; ≥1 adenoma of any size with villous or tubulovillous histology, serrated adenoma histology, or high-grade dysplasia | Colonoscopy in three years after initial polyp removal                                                                                                                                         |
| 1–2 small (<1 cm) tubular adenomas with no villous histology and no high-grade dysplasia                                                                                              | Colonoscopy in 5–10 years after initial polyp removal. Interval to be based on other factors, such as family history, prior colonoscopy findings, physician judgment, and patient preferences. |
| Multiple or large hyperplastic polyps suggestive of hyperplastic polyposis syndrome                                                                                                   | Colonoscopy every 6–12 months. These clients are best referred to a center with experience managing this syndrome.                                                                             |
| Small number of rectal hyperplastic polyps                                                                                                                                            | Colonoscopy in 10 years <sup>b</sup>                                                                                                                                                           |
| Normal colonoscopy                                                                                                                                                                    | Colonoscopy in 10 years <sup>b</sup>                                                                                                                                                           |

<sup>a</sup>Interval is based on colonoscopy being complete (i.e., the bowel preparation was adequate and cecum was reached) and neoplastic lesions being completely removed. If not, repeat colonoscopies should be performed at very short intervals (0–6 months).

<sup>b</sup>Interval should take family history into account. Patients with family history of colorectal cancer or adenomatous polyps in a first-degree relative (FDR) aged <60 years or ≥2 FDRs at any age should consider repeat colonoscopy within 5–10 years.

cm = centimeter



recall intervals agreed with program guidelines, and whether the local programs had accurately entered data in the CDB and managed cases appropriately.

The CRC testing methods changed over time: by 2006, 22 of 23 programs selected colonoscopy as the primary screening method (Figure 1). Factors that influenced this change included the time, expense, and difficulty of operating an annual FOBT-based screening program; the ease of case-managing clients who had no findings on colonoscopy and a 10-year recall; the inability of finding providers to perform sigmoidoscopy; the national shift toward colonoscopy as the most recommended CRC screening test;<sup>25,26</sup> and the ability of colonoscopy to both diagnose and treat some cancers as well as prevent cancer through polypectomy.

Programs additionally found it difficult to limit FOBT distribution to asymptomatic people of average risk. Hoping to reach the largest number of people with a low-cost screening test, several programs offered FOBT kits at health fairs and community events in the program's early years. Of those who took kits, more than 20% of those screened only with an FOBT in their first cycle were younger than 50 years of age (and not eligible for average risk screening) and more than 25% reported some GI symptom or risk and should have received a colonoscopy rather than an FOBT, according to program guidelines. Also, some jurisdictions initially found that starting CRC screening with an FOBT was more acceptable to clients who were not yet ready for endoscopy. Those with positive FOBTs who were ineligible for colonoscopy in the program due to income or insurance were notified of results and referred for colonoscopy; however, follow-up information on these clients was often difficult to obtain.

The income limit for eligibility increased over time in many jurisdictions. Programs found it difficult to recruit clients who had incomes  $\leq 100\%$  FPL. Clients with income eligibility matching that of the federal breast and cervical cancer program in Maryland (250% FPL) were easier to locate and recruit.

Recruitment and outreach efforts included linkages with medical clinics serving low-income/uninsured patients, physician offices, outreach to low-income workers at their worksites, hair salon/barber shop outreach, flyers in Laundromats and restrooms, and door-to-door outreach in low-income and minority neighborhoods. Despite these efforts, it was more difficult to recruit men than women. The percentage of men in the screening program has increased to only 36% in the last two years of the program despite outreach efforts (data not shown).

LHD staff remained integrally involved in their

clients' care after the diagnosis of cancer was made, whether or not treatment was funded by the CRF program. Anecdotally, counties that linked their clients to other payment methods for treatment invested a significant amount of time helping clients complete and submit applications for Medicaid, hospital charity care, and other sources of funding in a timely manner.

Since its inception, the Maryland program has consulted with numerous other state programs and with the Centers for Disease Control and Prevention CRC Screening Demonstration Program,<sup>27,28</sup> which funded Baltimore City as a CRC screening demonstration site in 2005.

## CONCLUSIONS

The Maryland CRF program has successfully shown that low-income and underserved members of the community will take advantage of CRC screening. We have also shown that a program based predominantly on colonoscopy is challenging but feasible. It is acceptable to clients and providers, and it is associated with good outcomes for primary and secondary prevention of CRC. If health-care reform is enacted, many underserved clients will gain access to CRC screening and other preventive services, but the public health roles of outreach, education, enrollment, and overcoming barriers through navigation will still be necessary to improve screening rates.

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The Institutional Review Board (IRB) of the MDHMH exempted this program evaluation project, and the UM IRB approved the project.

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# Law and the Public's Health

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This installment of *Law and the Public's Health* examines the evolution of U.S. health law in the context of the early detection and treatment of breast and cervical cancer. The column places this evolution in the context of Affordable Care Act implementation for the population generally and the low-income population specifically.

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## THE ACA: IMPLICATIONS FOR THE ACCESSIBILITY AND QUALITY OF BREAST AND CERVICAL CANCER PREVENTION AND TREATMENT SERVICES

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This installment of *Law and the Public's Health* examines the implications of legal interventions into health-care financing and service delivery as a mechanism for improving accessibility and quality of health care for low-income and vulnerable populations. The context for this examination is women's health, in particular breast and cervical cancer. Federal policy developments related to these two leading cancers in women are described, beginning with efforts in the early 1990s to improve access for women at risk for medical underservice and culminating with the passage of the Patient Protection and Affordable Care Act (hereafter, the Affordable Care Act [ACA]).<sup>1</sup> Following a review of pre-ACA policy, this article discusses the potential impact of the ACA as well as the potential ongoing role played by these earlier legislative policies.

### BACKGROUND

Breast and cervical cancer are the leading cancers among women. Low-income and minority women are less likely to be screened for both forms of cancer and more likely to die than non-minority, non-low-income women.<sup>2</sup>

To address this significant population health disparity, Congress began to take incremental legislative steps toward creating resources for screening and treatment. In 1990, Congress amended the Public Health Service Act to establish a National Breast and Cervical Cancer Early Detection Program (NBCCEDP).<sup>3</sup> The program provides grants to states to fund breast and cervical

cancer screening, support services, case-management services (added by amendments enacted in 1998),<sup>4</sup> and other services and activities aimed at developing greater capacity to serve at-risk populations. The Centers for Disease Control and Prevention reports that 8% to 11% of U.S. women are eligible to receive services through the NBCCEDP, which offers services to women with family incomes <250% of the federal poverty level (FPL). Since its 1991 implementation, the NBCCEDP has furnished nearly 10 million breast and cervical cancer screening exams to almost four million women, with diagnoses of more than 52,000 breast cancers, 2,800 invasive cervical cancers, and nearly 137,000 premalignant cervical lesions.<sup>3</sup>

Despite its success, the NBCCEDP had a decided shortcoming in its lack of any provision to finance the actual diagnosis, treatment, and follow-up care in the case of uninsured women whose exams reveal abnormal results. While charitable resources played an important role in this regard, the policy landscape lacked a reliable source of treatment financing to assure coverage for care. At the time of screening, some women may have been otherwise eligible for private insurance or Medicaid on the basis of parental status, pregnancy, or disability. But because of the medical underwriting process that underlies the individual health insurance market, it would be impossible for an uninsured woman with abnormal test results to buy a private policy at any price.

In response to this problem—and relying on a public financing approach to coverage that avoided the private insurance dilemma and had worked for other populations (e.g., pregnant women and people with disabilities) who are in immediate need of health care—Congress enacted the Breast and Cervical Cancer Prevention and Treatment Act (BCCPTA) in 2000.<sup>5</sup> The BCCPTA established a state Medicaid eligibility option to cover uninsured women, regardless of income or assets, whose screenings through NBCCEDP reveal abnormal results. By 2009, every state had adopted

the expansion option, although variations existed on important matters of program design and administration, particularly with respect to which women would be considered screened “under the program” and in the extent to which states aligned public health screening and Medicaid enrollment procedures.<sup>6</sup>

The BCCPTA extended coverage to thousands of uninsured (and uninsurable) women for breast and cervical cancer diagnosis and treatment. At the same time, however, the Medicaid expansions experienced serious shortcomings of their own; namely, the inability to enroll until an abnormality is disclosed. This barrier to early coverage (e.g., at the time of initial screening) potentially delayed entry into treatment, as it can take weeks to complete the enrollment process. The use of Medicaid as the basis of expansion also raised problems related to low Medicaid provider participation rates.<sup>7</sup> Indeed, one authoritative study concluded that delays in treatment access appear to have lengthened for certain women in the wake of the Act’s implementation, particularly for minority women.<sup>6</sup>

#### **WHAT THE ACA DOES TO PROMOTE BETTER ACCESS TO BREAST AND CERVICAL CANCER PREVENTION AND TREATMENT FOR LOW-INCOME AND MEDICALLY UNDERSERVED WOMEN**

An important question arises when federal policy-making evolves from incremental policy design aimed at addressing specific conditions or populations to broader-based interventions that are population wide and intended to address all health-care needs rather than any particular health problem. In the case of the ACA, it is possible to see the significant ways in which the breast and cervical cancer prevention and treatment environment can be expected to change for the women whose health needs were the focus of the NBCCEDP and the BCCPTA. It is also possible to begin to understand the ongoing role that both programs may continue to play despite the enactment of national health-care reform.

##### **Access to and the obligation of coverage**

Coverage affordability and accessibility regardless of health status represent the two fundamental tenets of the ACA. Beginning in January 2014, the private health insurance market will be transformed through a federal ban on the denial of coverage based on health status or preexisting condition.<sup>8</sup> Thus, it will be possible for all people to enroll in coverage regardless of their health status at the point of enrollment. As a result, women who have recently received abnormal screening results

cannot be denied coverage in the private insurance market. The ACA combines this antidiscrimination ban with the establishment of state health insurance Exchanges to greatly simplify the process of enrolling in an individual insurance plan in the case of women who do not have access to coverage through their employers or Medicare.

The ACA addresses financial access to coverage through two devices: (1) a Medicaid expansion to cover all low-income non-elderly adults with family incomes <133% FPL<sup>9</sup> and (2) the creation of advance refundable income tax credits for individuals with family incomes from 144% to 400% FPL.<sup>10</sup> The ACA provides that both forms of “insurance affordability” assistance (a term developed by the Department of Health and Human Services in proposed implementation regulations)<sup>11</sup> are to be made accessible through the Exchange enrollment process, thereby simplifying matters for individuals and families unsure of the subsidy for which they may be qualified.

The ACA also envisions continuous coverage. That is, Exchanges will operate not only at the point of initial enrollment, but also as the mechanism by which coverage and insurance affordability assistance both are renewed on an annual basis or more frequently if life circumstances necessitate changes in coverage (e.g., loss of a job with an attendant drop in income, divorce, or marriage).

The *quid pro quo* for this foundational elimination of barriers to coverage access and affordability is a requirement of coverage for all people who are eligible for coverage under the ACA (citizens and individuals legally present in the U.S.) and for whom affordable coverage exists.<sup>12</sup> The individual coverage requirement can be expected to not only significantly expand the reach of health insurance, but also to alter the timing of coverage to better ensure earlier access to preventive care and coverage in the event that a health condition does arise. As a result, the proportion of low-income and medically underserved women who are uninsured at the time they receive an abnormal screening result can be expected to decline.

##### **Access to quality prevention and treatment care**

The ACA provides for enrollment into qualified health plans (QHPs) in the case of women eligible for advance refundable premium tax credits through state Exchanges,<sup>13</sup> and into Medicaid benchmark coverage arrangements<sup>14</sup> for women whose incomes are low enough to qualify them for medical assistance. In both cases, coverage will reflect certain essential health benefits<sup>15</sup> that control for patient cost-sharing and that consist of ambulatory patient services, emergency



services, hospitalization, maternity and newborn care, mental health and substance use disorder services (including behavioral health treatment), prescription drugs, rehabilitative and habilitative services and devices, laboratory services, preventive and wellness services and chronic disease management, and pediatric services (including oral and vision care). Preventive services to be covered by all health plans (whether offered through Exchanges, Medicaid benchmark plans, employer products, or individual products purchased in the non-Exchange market)<sup>16</sup> are pegged to A and B recommendations of the U.S. Preventive Services Task Force and must be offered without cost-sharing, thereby removing barriers to recommended breast and cervical cancer exams, as both are recommended.<sup>17</sup>

The ACA provides for enrollment not simply into health-care financing arrangements, but also into QHPs and Medicaid benchmark coverage arrangements, in which coverage is tied to provider networks, as is the custom with modern insurance products. Whether plans are sponsored by state Medicaid agencies or Exchanges, they will be required to meet federal and state access and quality standards for both primary and specialty care<sup>18,19</sup> and will also need to satisfy quality performance benchmarks developed by both the federal government and state purchasers.<sup>16</sup> Furthermore, while cost-sharing for QHPs purchased through state health insurance Exchanges can be relatively steep (e.g., the standard plans available to women receiving advance refundable tax credits would have an actuarial value of only about 70%),<sup>20</sup> the ACA also imposes annual limits on out-of-pocket cost-sharing,<sup>21</sup> bars annual and lifetime limits on coverage,<sup>22</sup> and requires all plans to cover the routine costs associated with participation in clinical trials.<sup>23</sup>

In sum, beginning in January 2014, the ACA moves the population toward what might be thought of as a “new normal.” This new normal is a health-care environment in which most Americans are continuously enrolled in health insurance products that cover high-value preventive services, offer a reasonable range of diagnostic and treatment services, limit out-of-pocket exposure along with arbitrary annual and lifetime ceilings on coverage, and even promote access to advanced treatments through clinical trials. Enrollment is into health plans that not only finance care but that are also tied to networks furnishing care, thereby reducing the likelihood of coverage untethered from accessible treatments—a problem that historically has affected Medicaid.

## CHALLENGES

Despite its major advances, the ACA leaves important challenges in a breast and cervical cancer prevention and treatment context.

### Access to affordable coverage

The ACA leaves out certain women: (1) those who are not legally present in the U.S. and who, thus, do not qualify under the new system; and (2) women who will continue to face affordability barriers; that is, those for whom no plan is considered to be affordable under the law because their premium payments (whether to an employer or through their state Exchange) exceed 8% of their annual income.<sup>24</sup> For women facing affordability barriers, the Medicaid BCCPTA will remain an important source of last-resort health-care financing; for these women, as well as those not legally present, the NBCCEDP will continue to represent an essential source of affordable screening services. Furthermore, premium affordability programs will be needed, and, of course, subsidized care will be needed for women barred from coverage as a result of legal status issues.

In addition, breaks in coverage may be possible. The ACA provides for seamless subsidized coverage between Medicaid and state Exchanges. At the same time, the high number of individuals and families who experience periodic fluctuations in income is expected to create continuous enrollment challenges for states.<sup>25</sup> As a result, women may experience lapses in coverage as their life circumstances raise the risk of coverage breaks, and as they move from one source of coverage to another depending on the source of financial subsidy (i.e., Medicaid vs. advance premium tax credits).

### High out-of-pocket cost-sharing

While the coverage available to women through state insurance Exchanges will be broad, cost-sharing is also expected to be high, again because of built-in limits resulting from the limited level of advance premium tax credits. As the Institute of Medicine noted in its 2011 report on essential health benefits,<sup>26</sup> premiums will need to remain low to limit the number of people barred from coverage as a result of affordability issues. In other words, deductibles and cost-sharing will be high. Annual limits on out-of-pocket payments will play an important role in mitigating individual financial burdens in this regard, but they cannot eliminate them. Providers screening and treating lower-income women who cannot pay these fees, such as public hospitals, community health centers, and other safety-net providers, will continue to face serious revenue shortfalls, which will have to be recouped.



### Provider networks

Although health plans participating in Medicaid or Exchanges are expected to maintain provider networks that assure reasonable access to care, physicians already are in short supply (particularly in the primary care specialties), and in many parts of the country, specialty networks may be seriously limited. Interventions to extend care through the establishment of primary care access points in medically underserved communities and the creation of practice teams to support specialty care will be important. In this regard, the ACA provides for a major investment in community health center development to double health center capacity by 2019,<sup>27,28</sup> and the ACA also makes investments in new modes of service delivery whose purpose is to stretch available resources through more efficient approaches to care. But these investments alone cannot overcome the absence of effective cancer treatment programs in communities that experience problems of medical underservice, particularly if such programs eschew participation in provider networks offered through subsidized insurance arrangements.

### Patient outreach and support

As noted by the Medicaid and Children's Health Insurance Program Payment and Access Commission (better known as MACPAC), access is more than just provider availability and participation. It is also a function of whether patients are able to appropriately navigate the health-care resources that are available.<sup>7</sup> For this reason, programs that work alongside insurance—and indeed that eventually may be part of insurance provider networks—to assist women at risk for medical underservice through outreach and patient support activities will continue to play a central role for women facing long and difficult courses of cancer treatment and through survivorship.

### Access to clinical preventive care

It is true that clinical screening services for breast and cervical cancer will be available through ACA-level coverage, but plans will need provider networks to fully realize the promise of care. In medically underserved communities, access points such as NBCCEDP project grantees will continue to play an important role in extending entry-level care, even for women who are insured.

## IMPLICATIONS FOR PUBLIC HEALTH POLICY AND PRACTICE

The ACA's advances are enormous. At the same time, however, the ACA creates a new collection of challenges

for historically medically underserved patients. Many of these patients will be brought into a new system of health-care financing but will need access points and support services, particularly in the case of women who live in medically underserved communities where provider networks for both preventive and treatment care may be inadequate. Furthermore, the ACA will leave pockets of health-care financing lapses, particularly for women who are not legally present in the U.S., women who are facing insurance affordability barriers, and women who experience breaks in coverage. Finally, despite the breadth of coverage that the ACA will offer, its high cost-sharing structure may leave many women seriously underinsured or worse, without the means to pay their premiums.

Public health plays a central role in the formation and implementation of policy solutions on each of these matters: in assuring continuing screening and case-management services; in promoting health-care access standards for health plans participating in Medicaid or state Exchanges; in monitoring the accessibility and quality of care; in championing the preservation of state Medicaid coverage for uninsured women diagnosed with breast or cervical cancer in the event that such coverage is needed; and in supporting patients at risk of medical underservice who face the challenges of navigating prevention, treatment, and aftercare. Furthermore, resources will continue to be needed to support Medicaid coverage for the uninsured women who remain, as well as to assure necessary revenues for providers who treat large numbers of underinsured women. Finally, private resources also will continue to be important for women who, by virtue of their legal status, are barred from the new insurance regime.

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# NCHS Dataline

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The National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC) announces its 2012 National Conference on Health Statistics, which will be held August 7–8 in Washington, D.C. Data are now available from the first national survey of residential care facilities, and new reports describe the survey and present initial findings. Wireless-only phone use continues to increase in the United States, as shown in a new survey. Preliminary birth data for 2010 show record low teen birth rates and the lowest cesarean delivery rate in a decade.

## 2012 NATIONAL CONFERENCE ON HEALTH STATISTICS

The latest biennial conference to introduce researchers, analysts, and policy makers to the data resources of NCHS will be held August 7–8 in Washington, D.C., at the Renaissance Washington DC Downtown Hotel. The conference will include an all-day Learning Institute on August 6, where students will receive hands-on training in accessing and analyzing survey data and how to use selected data access tools. The Learning Institute will be followed by a two-day main conference, where attendees will learn about the latest developments at NCHS and hear from some of the nation's leaders in the fields of health, health data, and statistics. There is no charge for the conference, and those interested may sign up at <http://www.cdc.gov/nchs/events/2012nchs> to get on a mailing list to receive information about the conference and conference registration materials.

## DATA AVAILABLE FROM THE 2010 RESIDENTIAL FACILITIES SURVEY

Residential care facilities (RCFs) (e.g., assisted-living facilities and personal care homes) provide housing and supportive services to those who cannot live independently but generally do not require the skilled level of care provided by nursing homes. RCFs are not federally regulated, and state approaches to RCF regulation vary widely. The ability to provide a comprehensive picture of the long-term care (LTC) industry has been hampered by the lack of data on RCFs. Previous estimates of the size of the RCF sector varied depending on how RCFs were defined. NCHS conducted the National Survey of Residential Care Facilities (NSRCF) in 2010 to fill this important gap in the data on LTC facilities. The NSRCF joins the

ongoing surveys of nursing homes, home health, and hospice care.

NSRCF is a first-ever national probability sample survey that collects data on U.S. residential care providers, their staffs and services, and their residents. Included are RCFs consisting of assisted-living residences, board and care homes, congregate care, enriched housing programs, homes for the aged, personal care homes, and shared housing establishments that are licensed, registered, listed, certified, or otherwise regulated by a state.

A new report, “Design and Operation of the 2010 National Survey of Residential Care Facilities,”<sup>1</sup> describes the need for and objectives of the survey, the design process, survey methods, and data availability. The survey used a two-stage probability sampling design in which RCFs were sampled. Then, depending on facility size, three to six current residents were sampled. In-person interviews were conducted with facility directors and designated staffs; no interviews were conducted with residents. The survey instrument contained a facility screening module, facility- and resident-level modules, resident sampling module, and pre-interview worksheet. National data were collected on 2,302 facilities and 8,094 current residents. Two public-use files will be released. The facility and resident files include sampling weights to generate national estimates and design variables to calculate.

The first report of data from the NSRCF, “Residential Care Facilities: A Key Sector in the Spectrum of Long-Term Care Providers in the United States,”<sup>2</sup> has been published. In 2010, there were 31,100 RCFs providing 971,900 beds. About one-half of RCFs were small facilities with four to 10 beds. The remainder consisted of medium facilities with 11–25 beds (16%), large facilities with 26–100 beds (28%), and extra-large facilities with more than 100 beds (7%). One-tenth of all RCF residents lived in small RCFs, about the same percentage (9%) lived in medium facilities, and the majority resided in large (52%) or extra-large (29%) RCFs. The ownership type, chain affiliation, geographic location, and types of services provided by RCFs varied by facility size. The mix of facility sizes and the supply of residential care beds differed by region. About four in 10 RCFs served residents who were receiving LTC services paid by Medicaid. Large RCFs were more likely than small RCFs to be chain-affiliated and to provide occupational therapy, physical therapy, social services counseling, and case management.

## MORE AMERICAN HOMES HAVE ONLY WIRELESS TELEPHONES

Preliminary results from the January–June 2011 National Health Interview Survey (NHIS) indicate that the number of American homes with only wireless telephones continues to grow. More than three of every 10 American homes (31.6%) had only wireless telephones (also known as cellular telephones, cell phones, or mobile phones) during the first half of 2011—an increase of 1.9 percentage points since the second half of 2010 (29.7%) and up from 17.5% during January–June 2008.

The percentage of adults living in wireless-only households has also been steadily increasing. During the first six months of 2011, three of every 10 adults lived in wireless-only households. One year before that, one of every four adults lived in wireless-only households, and two years earlier, only one of every six adults lived in wireless-only households. In addition, nearly one of every six American homes (16.4%) received all or almost all calls on wireless telephones despite also having a landline telephone.

“Wireless Substitution: Early Release of Estimates from the National Health Interview Survey, January–June 2011”<sup>3</sup> presents the most up-to-date estimates available from the federal government concerning the size and characteristics of these populations. This report is published as part of the NHIS Early Release Program. Twice each year, NCHS releases selected estimates of telephone coverage for the civilian non-institutionalized U.S. population based on data from NHIS, along with comparable estimates from NHIS for the previous three years. The estimates are based on in-person interviews that NHIS conducts continuously throughout the year to collect information on health status, health-related behaviors, and health-care use. The survey also includes information about household telephones and whether anyone in the household has a wireless telephone.

## CESAREAN DELIVERY AND TEEN BIRTH RATES DOWN IN 2010

According to a new report, “Births: Preliminary Data for 2010,”<sup>4</sup> the cesarean delivery rate declined slightly for the first year in more than a decade to 32.8% of all births in 2010, from 32.9% in 2009. The percentage of births that were delivered by cesarean section had risen steadily from 1996 through 2009, although the pace of increase had slowed somewhat in recent years.

The birth rate for U.S. teenagers aged 15–19 years dropped 9% to 34.3 per 1,000 population in 2010, a record low for the nation and a drop from 37.9 per

1,000 population in 2009. The birth rate declined to historic lows for younger and older teenagers and for all racial/ethnic and Hispanic-origin groups.

The preliminary number of U.S. births was 4,000,279 in 2010, which was 3% lower than in 2009; the general fertility rate (64.1 per 1,000 women aged 15–44 years) and the total fertility rate (1,932.0 births per 1,000 women) also declined in 2010 by 3% for each. The number of births and rates declined for all racial/ethnic and Hispanic-origin groups in 2010. The birth rates for women in their 20s and 30s declined in 2010; the birth rate for women aged 20–24 years dropped 6% to 90.0 births per 1,000 women, the lowest level ever reported. The birth rate for women in their early 40s rose in 2010—the only age-specific rate to show an increase. The birth rate and the number of births for unmarried women each declined for the second consecutive year; the rate fell 4% to 49.9 per 1,000 unmarried women. The percentage of births to unmarried women declined slightly to 40.8% in 2010. The preterm birth rate fell for the fourth consecutive year to 11.99%; the low birthweight rate remained virtually unchanged at 8.15%.

The report presents preliminary data on births, birth rates, and selected maternal and infant health characteristics for the U.S. in 2010. The findings are based on 100% of registered vital records occurring in calendar year 2010, which were received and processed by NCHS as of August 31, 2011. Trends in the preliminary reports for 1995–2009 births were confirmed by the final vital statistics for each year, and comparisons were based on the final data for 2009 and earlier years.

NCHS Dataline was prepared by Sandra S. Smith, MPH, Communications Consultant at the National Center for Health Statistics, Centers for Disease Control and Prevention.

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## *On Linkages*

### USING GIS FOR ADMINISTRATIVE DECISION-MAKING IN A LOCAL PUBLIC HEALTH SETTING

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Geographic information systems (GIS) include tools that capture, store, analyze, and manage data linked to geographic locations. These tools were quickly adopted by fields such as environmental management and biological sciences since the first use of GIS in the 1970s.<sup>1</sup> However, in recent years, GIS has been increasingly used within the realm of health care as a tool to better understand spatial relationships of health and illness.<sup>2-6</sup> GIS has also become a valuable tool in assuring access to hospitals,<sup>7,8</sup> palliative care,<sup>9</sup> and primary care for vulnerable and underserved populations.<sup>10-12</sup> Using GIS as a tool to determine where clinics can be placed to maximize access to care is particularly relevant for primary care services associated with ongoing changes to our health-care system, especially in light of the Patient Protection and Affordable Care Act of 2010.<sup>13</sup> Therefore, GIS may serve as a tool to aid decision makers in strategizing clinic placement and managing the forthcoming demand on health-care resources.

Public health often serves as a “provider of last resort” for vulnerable and underserved populations<sup>14</sup> and may face a heavy portion of the burden of increasing health-care demands due to expanded coverage expected as a result of health-care reform.<sup>15</sup> Studies of GIS’ use in local or county public health centers are scarce except for those conducted in international settings.<sup>9,12,16,17</sup> Instead, much of the literature documenting GIS use by public health within the United States has been conducted at the state<sup>18</sup> or national<sup>11,19-22</sup>

level, and the majority of these GIS studies are concerned with disease surveillance<sup>23,24</sup> and environmental health.<sup>17,24-26</sup> More examples of how GIS can be used at the local public health level in the U.S. are needed, particularly regarding how GIS can be leveraged for administrative decision-making. This study provides such an example.

In 2009, the Jefferson County Department of Health (JCDH) had seven primary care centers, primarily located in low-income areas of Birmingham, Alabama, and surrounding municipalities. The majority of patients were uninsured or publicly insured (i.e., insured by Medicaid and the Children’s Health Insurance Program). Productivity measures from 2008 indicated that three of the seven primary care centers had declining trends in the number of patients served. The goal of this study was to use GIS analysis to objectively develop criteria to assist JCDH decision makers in consolidating any of the seven primary care centers without affecting patients’ access to health services.

The purpose of this article is to describe a way in which GIS can be used for administrative decision-making at the local public health level. Specifically, we present data that guided decisions regarding the placement of county-level public health primary care centers, including center closings, consolidation, and/or the development of new center locations. This study will be of interest to public health decision makers, policy makers, and other stakeholders interested in using GIS, especially regarding decisions on primary care center locations or other administrative issues.

### METHODS

To determine primary care center placement, we used a combination of the patient origin and distance measure approaches.<sup>27,28</sup> Using GIS software, we analyzed the proportion of the overall JCDH patient population served by each primary care center and the estimated straight-line distance patients were traveling to their health center of choice.

Patient addresses, which are routinely collected in the organization-wide electronic medical record, were extracted and geocoded to attach a latitude and

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longitude for the patient's residence using MapMarker® 12 software.<sup>29</sup> The locations for the seven primary care centers for 2008 and 2009 were also geocoded using the same software. All addresses were imported into ArcView® version 9.3 for map rendering and analysis.<sup>30</sup> We used Hawth's Analysis Tools to determine the miles that individual patients traveled to their health centers.<sup>31</sup> ArcView's buffer and selection tool was used to determine the percentage of patients who live within a certain mile radius of the primary care centers.

Patients were grouped by the purpose of their most recent service: adult health, child health, or family planning. All patients who had a visit from January 1 to May 31, 2009, were used to determine the distance patients would drive to their primary care centers. Hawth's Analysis Tool estimated the distance in miles that residents traveled to the primary care center of their most recent visit. Outliers, such as out-of-state patients and those living more than 10 miles beyond the county boundaries, were excluded from the dataset. We used the ArcView buffer and selection tool to determine the total number and percentage of patients who live within an optimal mile radius of the primary care center, as determined by the distance between points analysis. Lastly, we plotted census tract data on the proportion of citizens at or below the federal poverty level in relation to public health primary care center placement.

## RESULTS

The seven JCDH primary care centers treated 25,349 patients from January 1 to May 31, 2009 (Table 1). Figure 1 shows the locations of primary care centers in 2009 and the size of the population eligible for Medicaid. A total of 23,967 (94.5%) of the patient addresses were geocoded and included in the analyses. The mean distance JCDH patients traveled to the primary care center of their most recent visit ranged from 4.8 to 9.0 miles, with an average of 6.5 miles traveled. A review of patient residences indicated that the majority of patients are located within a six-mile radius of their primary care center (Figure 2). Because the majority (89%) of JCDH patients lived within six miles of a primary care center, regardless of service type, six miles was determined to be a reasonable distance for JCDH patients to travel for health services and was used as a catchment measure around the primary care center (Table 2).

Three of the public health primary care centers in the western portion of the county treated patients whose addresses overlapped within the six-mile radius with more than one health center. Given that two of

these primary care centers had continuously decreasing patient visits, it was important to determine if all three centers in the western part of the county were necessary, whether one or more could be consolidated, or whether a new location would be more appropriate. Using the central latitude and longitude of the addresses of patients living in the western portion of the city, we identified a potential area for a new primary care center that would serve patients from all three primary care centers. This new location was factored into the model of the overall distances patients travel to their primary care centers.

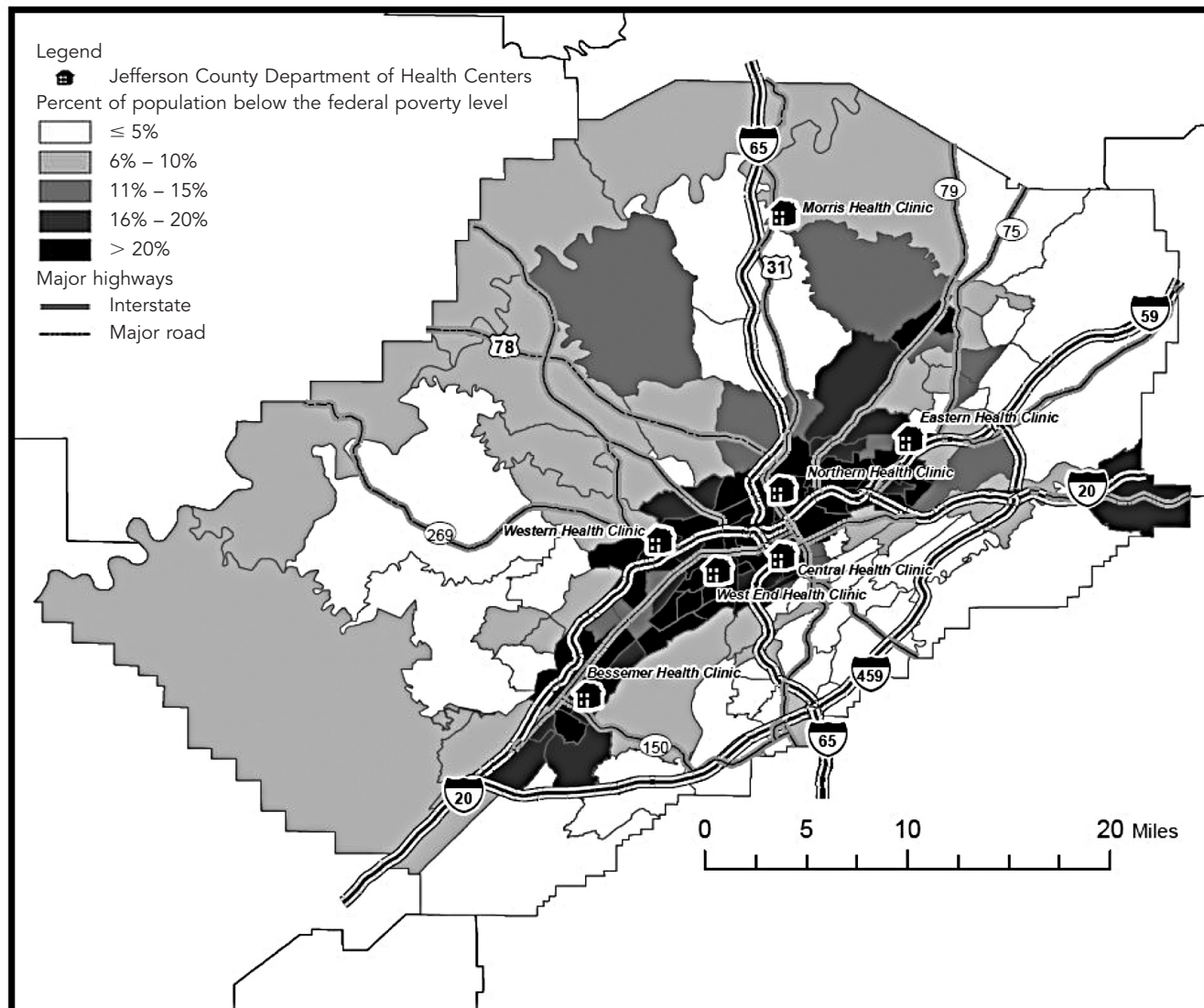
Primary care centers located in the center of Birmingham, the east side of the city, and the one rural location (Morris Health Center) would remain open. The decision to replace the three current primary care centers in the western region with one new consolidated center (Figure 3) involved choosing a location that would maximize access for patients currently being treated by the existing centers. By downsizing from seven primary care centers to four, it was found that

**Table 1. Jefferson County Department of Health patient and primary care center characteristics: Jefferson County, Alabama, 2009**

| <i>Patient characteristic</i>                                                       | <i>Frequency<br/>N (percent)</i> |
|-------------------------------------------------------------------------------------|----------------------------------|
| Race                                                                                |                                  |
| Black                                                                               | 20,063 (79.2)                    |
| White                                                                               | 4,912 (19.4)                     |
| Asian                                                                               | 164 (0.7)                        |
| Pacific Islander                                                                    | 35 (0.1)                         |
| American Indian                                                                     | 15 (0.1)                         |
| Multiracial                                                                         | 160 (0.6)                        |
| Ethnicity                                                                           |                                  |
| Non-Hispanic/Latino                                                                 | 21,833 (86.1)                    |
| Hispanic/Latino                                                                     | 3,516 (13.9)                     |
| Gender                                                                              |                                  |
| Female                                                                              | 18,351 (72.4)                    |
| Male                                                                                | 6,998 (27.6)                     |
| <i>Distance to patient residences (in miles) by primary care center<sup>a</sup></i> | <i>Mean (median)</i>             |
| Central Health                                                                      | 9.0 (8.3)                        |
| Eastern Health                                                                      | 7.5 (5.7)                        |
| Northern Health                                                                     | 6.9 (6.1)                        |
| Western Health                                                                      | 5.2 (3.8)                        |
| West End Health                                                                     | 5.1 (3.5)                        |
| Bessemer Health                                                                     | 4.8 (3.3)                        |

<sup>a</sup>Morris Health Center was not included in the list because it is a rural center and, unlike the other health centers, does not offer a full range of services.

**Figure 1. Jefferson County Department of Health primary care center locations and percent of population below the federal poverty level: Jefferson County, Alabama, 2009<sup>a</sup>**



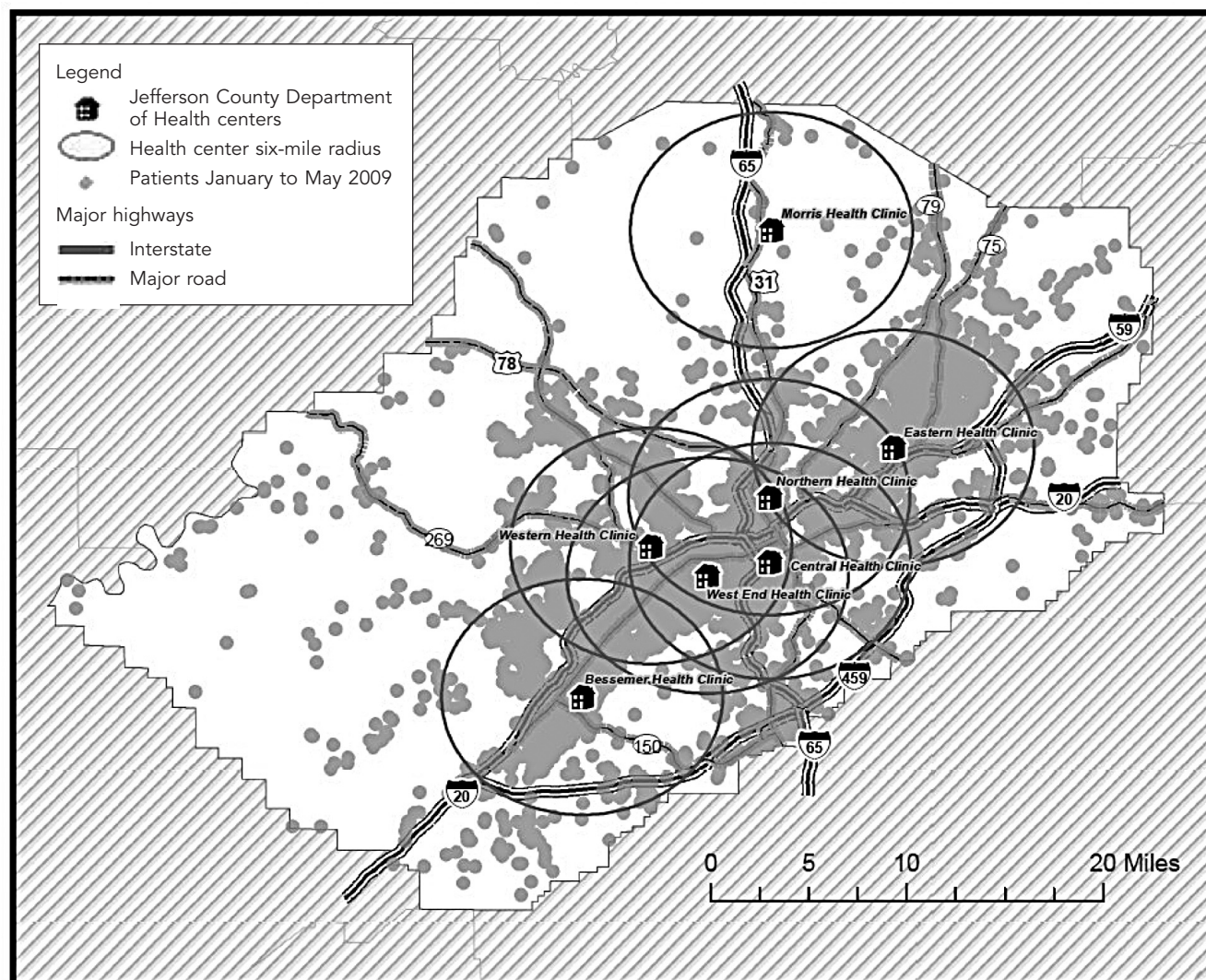
<sup>a</sup>Data obtained from Census 2000 for population below federal poverty level by census tract

there would be a 4% reduction in the portion of JCDH patients served within a six-mile radius of their homes (from 89% to 85%). Specifically, among the patients currently seen in the three primary care centers in the western region, the new location would be beneficial to the patients visiting adult health services, with a 7% gain in the percentage of patients within six miles of a primary care center. On the other hand, there would be a decrease in proximity of 6% among patients using the child health or family planning services.

## DISCUSSION

GIS has the potential to serve as a valuable tool to aid in local public health administration and decision-making. This study, which was conducted by a county health department, provides an example of how GIS can be used for managing and determining primary care center locations in such a setting. Because public health often predominantly provides primary care services to low-income populations, local public health decision makers will need to maximize the efficiency of operations when managing the upcoming primary

**Figure 2. Primary care center locations and patient residences with six-mile catchment: Jefferson County, Alabama, 2009**



**Table 2. Jefferson County Department of Health patient population served within six-mile radius of primary care centers: Jefferson County, Alabama, 2009**

| Type of health service    | Placement as of 2009 <sup>a</sup> | Proposed new placement <sup>b</sup> |
|---------------------------|-----------------------------------|-------------------------------------|
|                           | N (percent)                       | N (percent)                         |
| Adult health <sup>c</sup> | 2,329 (78)                        | 2,548 (85)                          |
| Child health              | 10,892 (89)                       | 10,253 (83)                         |
| Family planning           | 8,074 (93)                        | 7,577 (87)                          |
| Total                     | 21,295 (89)                       | 20,378 (85)                         |

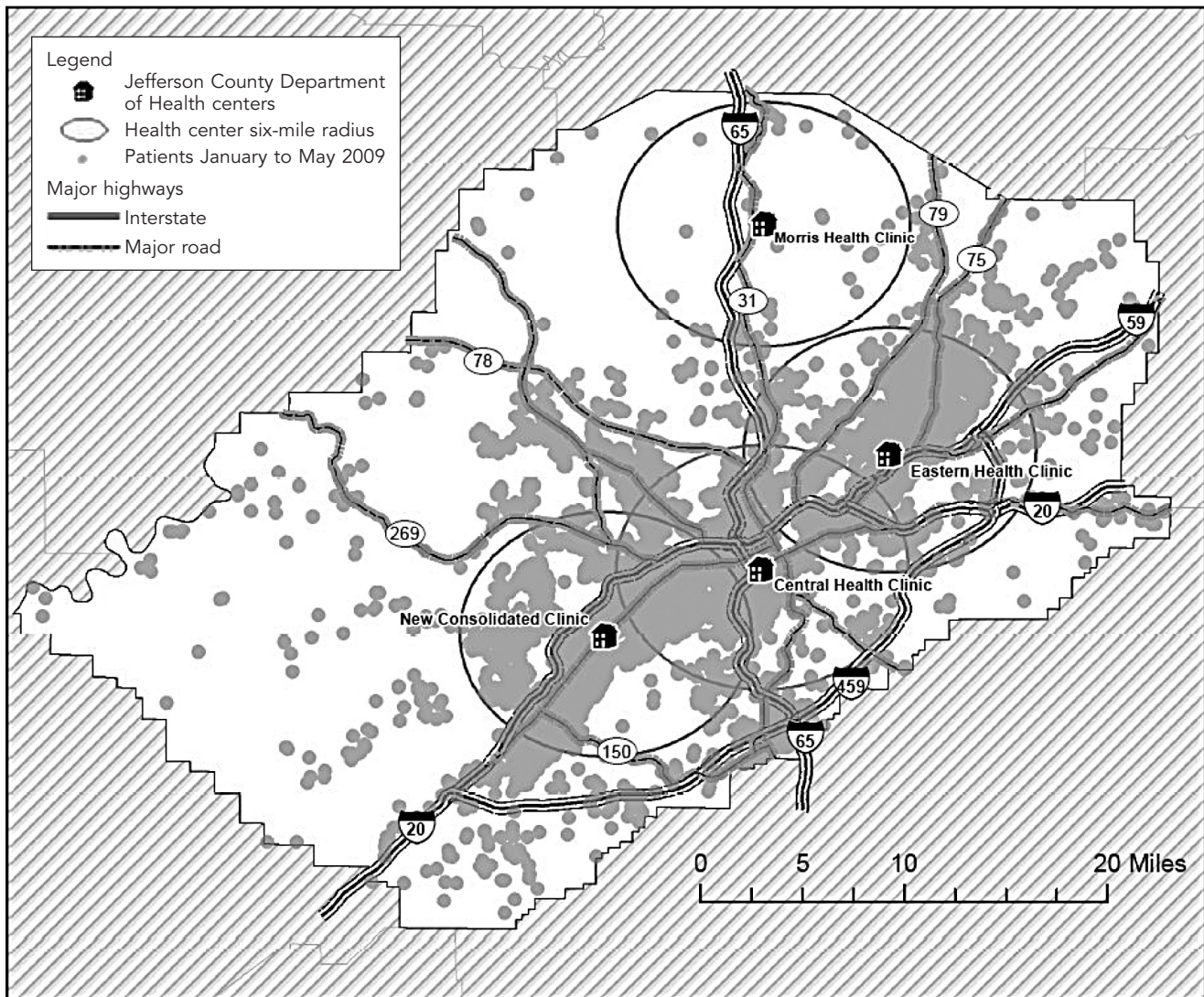
<sup>a</sup>Placement includes Bessemer, Central, Eastern, Morris, Northern, West End, and Western health clinics.

<sup>b</sup>Proposed placement is after consolidating the three clinics in the Western region of the county into a new clinic. This includes Central, Eastern, Morris, and the new consolidated clinic.

<sup>c</sup>Percent represents the population served by the five clinics that offer adult health services (Bessemer, Central, Northern, West End, and Western health clinics).



**Figure 3. Revised primary care center locations and patient residences with six-mile catchment: Jefferson County, Alabama, 2009**



care demands of the anticipated Medicaid expansion associated with health-care reform.<sup>13</sup>

Given our findings, GIS can be used as a tool in administrative decision-making on how to most efficiently assure patient access to care. Prior to the current analysis, JCDH leadership was considering closing the northern primary care center because patient volume there was declining. Leaders were also contemplating establishing a new primary care center in the north-central area of the county, where it was anecdotally believed a large number of Medicaid patients were living. However, the results of the current GIS analyses

indicated that few patients in that area would likely qualify for Medicaid, suggesting that a primary care center placed there would not be justifiable. Instead, based on the empirical GIS analysis, decision makers chose to consolidate the three primary care centers in the western section of the county. Consolidation allowed JCDH to retain the same staff and capacity while reducing the fixed costs associated with the upkeep and maintenance of three facilities, with minimal or no changes in patient travel distances. Consolidating three primary care centers into one new center and closing the northern primary care center

provided patients in Jefferson County with four more strategically placed care centers.

### Limitations

Although GIS offers valuable information for decision-making, there were a few limitations associated with this study. First, due to software limitations, we used the straight-line method of estimating the distances from patients' homes to their primary care centers. Straight-line estimates only approximate actual travel distances. Thus, using a network analyst software to measure drive time would have improved the precision of our analysis. Furthermore, we recognize that using patients' residences may be a limitation given that some patients may travel from their workplaces or schools to the primary care center. Nevertheless, residences represented the most complete data available for this study. Lastly, we recognize that an important next step is to calculate the actual cost savings associated with the consolidation of the superfluous primary care centers. Doing so will allow for the important quantification of cost savings that stemmed from this decision.

### CONCLUSIONS

Overall, using GIS to visually depict the patients served by JCDH provided valuable information that assisted in facilitating primary care center management and organizational change. This information provides a valuable example of the usefulness of GIS for local public health decision-making. GIS and other innovative analytical tools will be essential for keeping public health agencies on the cutting edge of managing populations and their health, especially given the expanding role that public health will play in our health-care system's increasing focus on efficiency and effectiveness. Future GIS studies should include examinations of the reliability or validity of GIS data, or the cost-effectiveness of using GIS in the local public health setting, especially considering that it is already being employed as a tool in myriad public health activities (e.g., environmental management, community health intervention mapping, and emergency and disaster response activities).

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