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## EXECUTIVE PERSPECTIVE



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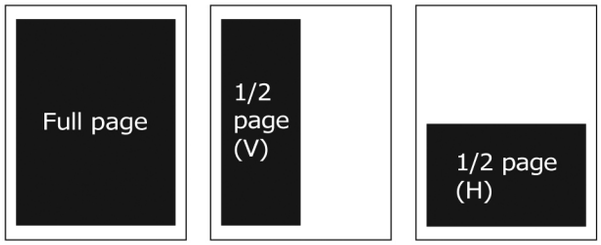


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# A Message from the Editor

With this issue of *Public Health Reports* (*PHR*), we initiate a new column, *Executive Perspective*. The purpose of the column is to give senior public health officials an opportunity to discuss timely public health topics in concert with national commemorations of that same theme. In this inaugural column, Deputy Surgeon General, Rear Admiral Boris Lushniak, a dermatologist, provides up-to-date information on ultraviolet (UV) radiation as we observe UV Awareness Month. Look for future columns from other senior officials, who will delve into a variety of contemporary issues.

I would also like to call your attention to a few special columns in this issue of *PHR*. If you are a regular reader, you know that we have rotating columns that span a variety of public health topics. One of our popular columns is *Law and the Public's Health*. In recent issues of *PHR*, we have published articles discussing various aspects of the Patient Protection and Affordable Care Act (ACA).[1] In this issue, Espinosa explores the rights of individuals to appeal decisions made by private insurers and the impact of the ACA on those rights. Also noteworthy this month is our *Local Acts* column in which Bodach et al. describe how monitoring of acute HIV infections has been integrated into regular public health surveillance activities in New York City, a model that could be emulated by other local health departments.

Lastly, we have an entry in our *Environmental Health* column. Licudine et al. present an interesting and insightful discussion on the aftereffects of fireworks on ambient air, measuring exposure to and documenting the presence of a variety of contaminants after fireworks celebrations in Hawaii. This topic is particularly timely as we enter the summer season and head off to many celebrations in which fireworks are used.

In another timely article for summer, Helmkamp et al. compared state-specific all-terrain vehicle (ATV) fatality rates, grouping states according to helmet, training, and licensure requirements. They found that males accounted for 86% of ATV fatalities, and that while helmet-use requirements seemed to slightly mitigate fatalities, training requirements did not.

This issue features one other article that's especially relevant during the summer months. Lindsey et al. present an assessment of ArboNET, the U.S. national arboviral surveillance system, which was developed initially to monitor West Nile virus infections in humans, mosquitoes, birds, and other animals, but has been expanded to include other nationally notifiable domestic arboviruses as well as some travel-associated viruses. As a result of their assessment, changes to ArboNET have already been implemented, while further recommendations are being explored to ensure that the system continues to be a useful tool for national surveillance of arboviral diseases.

A special thanks to all our public health practitioners who work diligently to make sure the summer season is safe, healthy, and fun for all.

Janice Huy, MS, RD, LD
Captain (Retired), USPHS

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# Surgeon General's Perspectives

## A NEW SURGEON GENERAL'S REPORT: PREVENTING TOBACCO USE AMONG ADOLESCENTS AND YOUNG ADULTS

VADM Regina M. Benjamin,
Surgeon General

Far too many adolescents and young adults use tobacco, resulting in immediate heart and lung damage from smoking and placing them at risk for a lifetime of addiction to nicotine. While progress has been made in the fight against tobacco use in young people, more than 3.6 million middle and high school students still smoke cigarettes. (This figure was obtained by multiplying the current smoking prevalence in middle and high school [from the 2009 National Youth Tobacco Survey][1] by the number of students enrolled in middle and high school [from U.S. Census 2009][2]). Furthermore, targeted marketing encourages more young people to take up this harmful habit every day. We must reinvigorate our efforts to tackle the immediate and long-term health effects from tobacco use in young people.

In March, I released a new Surgeon General's Report, "Preventing Tobacco Use Among Youth and Young Adults." The report examines in detail the epidemiology, health effects, and causes of tobacco use among adolescents (aged 12–17 years) and young adults (aged 18–25 years). Additionally, it highlights effective strategies to prevent young people from using tobacco.[3] Nearly all tobacco use begins during adolescence and young adulthood, and young adults are a prime target for tobacco advertising and marketing activities.

Expenditures for marketing and promotion of tobacco products exceed $1 million an hour—more than $27 million a day—in the United States alone.[4,5] These targeted messages and images portray smoking as an acceptable, appealing activity for young people. Advertising for tobacco products is prominent in retail stores, and new products have emerged that young adults, teens, and even younger children may find attractive. For example, smokeless tobacco products that don't require spitting or that dissolve like mints have recently been introduced. Additionally, more white male high school students are using smokeless tobacco than ever before, and the use of more than one type of tobacco product is common among young people. Cigar smoking is now common among high school males and may be increasing among other groups.[1]

Each day, more than 1,200 people die due to smoking. For every smoker who dies, at least two new young people or young adults become regular smokers, and 90% of these replacement smokers smoke their first cigarette by age 18.[6] We can and must prevent these young individuals from initiating smoking, and from progressing from smoking occasionally to smoking every day.

Out of every three young smokers, only one will quit, and one of those remaining smokers will die from tobacco-related causes. Most young people never consider the long-term health consequences associated with tobacco use when they start smoking. Furthermore, nicotine, a highly addictive drug, causes many people to continue smoking well into adulthood, often with deadly consequences.

While the long-term health effects of tobacco use are well-known, initiating smoking early in life has substantial health risks that begin almost immediately. These risks include serious early cardiovascular damage and a slowing of lung growth and development. This lung damage is permanent, causes immediate shortness of breath, and increases the risk of chronic obstructive pulmonary disease and other pulmonary diseases later in life.

Many initiatives have been launched to help counter the influences that encourage young people to begin tobacco use. The Tobacco Master Settlement Agreement in 1998 curtailed much of the advertising that was

particularly appealing to young people.[7] The passage of 2009 legislation giving the Food and Drug Administration the authority to regulate tobacco products and tobacco advertising is another important means of helping decrease the appeal of tobacco use to this population.[8] Coordinated, multicomponent interventions that include mass-media campaigns, community programs, comprehensive statewide tobacco-control programs, price increases, and school-based policies have also proven effective in preventing the onset of tobacco use among young people and young adults.[1]

We know what works to prevent tobacco use among young people. The science contained in this and other Surgeon General's reports provides us with the information we need to prevent the needless suffering of premature disease caused by tobacco use and save millions of lives. By strengthening and continuing to build upon effective policies and programs, we can help make our next generation tobacco free.

Regina M. Benjamin, MD, MBA
VADM, U.S. Public Health Service
Surgeon General

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# Executive Perspective

As public health professionals, you undoubtedly use the national health observances to help heighten awareness of important health topics. In this column, RADM Boris Lushniak provides a unique perspective on ultraviolet (UV) radiation awareness to coincide with UV Awareness Month in July. For more information on UV Awareness Month, go to http://www.healthfinder.gov/nho/JulToolkit.aspx.

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

## HERE COMES THE SUN

Boris D. Lushniak, MD, MPH

As we approach another summer season, we're all reminded of the fun and activities that those "dog days" of summer bring. Certainly, the milder weather allows us to venture into the great outdoors and pursue the recommendations of the National Prevention Strategy.[1] For example, adults should engage in at least 150 minutes of moderate-intensity activity each week, and children and teenagers should be involved in at least one hour of activity each day. Whether you engage in outdoor physical activity or outdoor recreational activities such as boating, swimming, attending sporting events, picnicking, or relaxing, regardless of the season, your skin is vulnerable and needs to be protected.

The culprit is ultraviolet (UV) radiation, which is a form of radiation that comes from the sun, tanning beds, and sunlamps. UV radiation can penetrate and change the cells within the layers of the skin. Immediate effects of UV radiation exposure include tanning and burning of the skin. Excessive chronic exposure to UV radiation can change the texture of your skin, cause wrinkling and premature skin aging, and lead to cataract formation in the eyes. More importantly, chronic UV radiation exposure is linked to skin cancer. A simple way of noting the intensity of UV radiation on any given day is by paying attention to the UV Index. This scale, which was developed by the Environmental Protection Agency and the National Weather Service, is often reported in newspapers, on weather broadcasts, or on the Internet.[2] The scale ranges from 1 to 11+, with a UV Index of 8–10 presenting a very high risk of harm from unprotected sun exposure.

The World Health Organization, International Agency for Research on Cancer lists UV radiation as carcinogenic to humans.[3] Basal- and squamous-cell skin cancers are the most common cancers in the United States, with more than three million people affected every year. Most skin cancers are curable but do require surgical procedures. The most dangerous and deadly skin cancer is melanoma. This year, more than 76,000 cases of melanoma will be diagnosed in the U.S., and more than 9,000 deaths will result from melanoma.[4]

The best way to fight skin cancer is to prevent it. Reducing exposure to UV radiation can help decrease the risk of skin cancer. Parents and caregivers should pay special attention to children by limiting their exposure to UV radiation. Reducing UV radiation exposure is a multifaceted process that includes (*1*) properly using sunscreen; (*2*) seeking shade, especially between 10 a.m. and 4 p.m.; (*3*) covering the head with a wide-brimmed hat; (*4*) shielding the skin with appropriate clothing (e.g., some garments have UV protection factor labels); and (*5*) protecting the eyes with UV-blocking sunglasses. In addition, one should avoid artificial sources of UV radiation, such as sunlamps or tanning beds.

As for the proper use of sunscreen, the American Academy of Dermatology recommends applying a broad-spectrum (covering both UVA and UVB rays) sunscreen with a sun protection factor (SPF) of ≥30 to all exposed skin.[5] The sunscreen should be reapplied every two hours and after sweating or swimming.

The regulatory world of sunscreens is changing, and hopefully these changes will provide more accurate information to the public. Final Food and Drug Administration (FDA) regulations that will go into effect in June 2012 will establish standards for testing the effectiveness of sunscreens and will require specific labeling to reflect those results.[6] These new regulations will require specific criteria for sunscreens to be labeled as "broad spectrum" and "water resistant." Only sunscreens that pass the FDA's broad-spectrum test procedure, which measures a product's UVA protection relative to its UVB protection, may be labeled as "broad spectrum." Water-resistance claims must indicate whether the sunscreen remains effective for 40 minutes or 80 minutes while swimming or sweating,

based on standard testing. Only sunscreens that are broad spectrum and have an SPF rating of ≥15 will be labeled with the following statement: "If used as directed with other sun protection measures . . . reduces the risk of skin cancer and early skin aging, as well as helps prevent sunburn." Sunscreens that are not broad spectrum or are broad spectrum but only have SPF ratings of 2–14 will be labeled as follows: "This product has been shown only to help prevent sunburn, not skin cancer or early skin aging."

Other regulatory actions are being taken at local and state levels to limit exposure to UV radiation in tanning beds. For example, in October 2011, California banned the use of UV tanning devices by children and teenagers younger than 18 years of age.[7]

Skin cancer remains a national priority. Healthy People (HP) 2020 focuses on science-based national objectives for promoting health and preventing disease. The HP 2020 goals focus on reducing the melanoma death rate and increasing behaviors that reduce exposure to harmful UV radiation and avoid sunburn.[8]

Do your part to promote the National Prevention Strategy—"working together to improve health and quality of life for individuals, families, and communities by moving from a focus on sickness and disease to one based on prevention and wellness"[1]—by protecting yourself and those you love from the harmful effects of the sun and artificial sources of UV radiation. As the Australians say: "Slip, slop, slap, seek, slide." That is, slip on a shirt, slop on the sunscreen, slap on a hat, seek shade, and slide on the sunglasses.

Boris Lushniak is Deputy Surgeon General in the U.S. Public Health Service, Office of the Surgeon General, Washington, D.C.

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The findings and opinions expressed in this article are those of the author and do not necessarily represent the official position of the Office of the Surgeon General.

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# State-Specific ATV-Related Fatality Rates: An Update in the New Millennium

James C. Helmkamp, MS, PhD[a]
Mary E. Aitken, MD, MPH[b]
James Graham, MD[b]
Corey R. Campbell, MS[a]

## ABSTRACT

**Objectives.** We compared state-specific all-terrain vehicle (ATV) fatality rates from 2000–2007 with 1990–1999 data, grouping states according to helmet, training, and licensure requirements.

**Methods.** We used the CDC WONDER online database to identify ATV cases from 2000–2007 and calculate rates per 100,000 population by state, gender, and age.

**Results.** ATV deaths ($n$=7,231) occurred at a rate of 0.32 per 100,000 population. Males accounted for 86% of ATV-related deaths at a rate that was six times that for females (0.55 vs. 0.09 per 100,000 population, respectively); 60% of the male deaths occurred in the 15- to 44-year age group. With the exception of the two oldest age categories, rates were consistently higher in the no-helmet-law group. Both the number and rate of ATV-related deaths increased more than threefold between 1990–1999 and 2000–2007. West Virginia and Alaska continue to have the highest ATV fatality rates (1.63 and 2.67 ATV deaths per 100,000 population, respectively).

**Conclusions.** Helmet-use requirements seem to slightly mitigate ATV-related death, but training requirements do not. For policy to be effective, it must be enforced.

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Since their introduction in the 1970s, all-terrain vehicles (ATVs) have been used in a variety of recreational activities and in numerous occupational settings in the United States and other nations. Unfortunately, injuries and deaths related to the use of these vehicles have been a persistent problem throughout this period and have been increasing in recent years.[1–4] According to the U.S. Consumer Product Safety Commission (CPSC), recreational ATVs in use have increased 126%, from 4.2 million units in 2000 to 9.5 million units in 2007; estimated deaths have increased 56% between 2000 and 2007, from 551 to 857 deaths annually (reporting is ongoing). Furthermore, estimated injuries seen in emergency departments increased 23% between 2000 and 2007, from 92,200 to 150,900 injuries annually.[1]

A variety of strategies to decrease ATV-related injuries have been attempted, including legislation, public awareness and education, hands-on training, and modifications in vehicle design. A few recent studies describing various ATV educational efforts directed at young people and mixed age groups have focused on behavioral change resulting from focus groups, videos, and training programs. Aitken and colleagues conducted multiple focus group meetings with both adult and adolescent ATV riders, discussing riding habits and use of protective gear. They concluded that licensing, training requirements, and improved enforcement of existing laws should be strategic components of ATV safety campaigns.[5] Burgus et al. conducted a survey of young people aged 12–20 years at a national agricultural convention to identify safety-related behaviors, injuries, and effects of ATV safety training. They concluded that an understanding of the behavior of young ATV operators should be considered in the design of ATV safety programs and educational materials.[6] Williams et al. found that using a brief ATV safety video in a required statewide hunter education course generally increased safety knowledge.[7]

Consistent with other areas of injury prevention and control, policy measures to reduce risky ATV use have been passed in many states, including helmet-use requirements, training requirements, and restrictions on use of the vehicles related to driver age and other factors. Studies of the impact of these policies have demonstrated somewhat mixed results. A 2001 report of state-specific death rates resulting from ATV crashes from 1990–1999 reported that the seven states without safety legislation had a collective death rate (0.17 deaths per 100,000 population) that was twice that of the other states (0.08 deaths per 100,000 population), all of which had some level of ATV legislation.[8] West Virginia (0.70 ATV deaths per 100,000 population), one of the states in the former group, and Alaska (0.55 ATV deaths per 100,000 population), in the latter group, experienced the highest rates during the decade.

Rodgers used a different methodology to study factors associated with ATV mortality rates during the same time period and reported that West Virginia (6.33 ATV deaths per one million population) and Alaska (5.99 ATV deaths per one million population) had the highest rates; these two states accounted for about 7% of ATV-related deaths, despite representing less than 1% of the U.S. population.[9] Because these studies were both cross-sectional in nature covering a 10-year period, they did not assess trends and changes in rates that may have resulted from nationwide education and training efforts dictated by a 10-year consent decree between CPSC and ATV manufacturers initiated in 1988.[10] Rodgers noted that many of the safety laws were only applicable for part of the period, depending on when they went into effect. He also noted that, while state safety requirements are expected to reduce the mortality rate, the presence of high ATV mortality rates may spur the enactment of states' safety requirements.[9]

Upperman et al. reported an overall fatality rate of 0.09 ATV deaths per 100,000 population among children younger than 16 years of age for the period 1982–1998 and concluded that current legal and regulatory standards (as of 1998) had a low probability of decreasing pediatric ATV-related mortality.[11] In a brief editorial, Helmkamp reported a 181% increase in the overall mortality rate in West Virginia, from 0.70 per 100,000 population in 1990–1999 to 1.94 per 100,000 population during 2000–2006; however, it should be noted that West Virginia enacted its safety legislation in 2005.[12] A study by Helmkamp and colleagues reported that, during 2000–2005, there were 1,043 ATV deaths in children aged 15 years or younger (a rate of 0.27 per 100,000 population) compared with 4,161 deaths among adults (a rate of 0.31 per 100,000 population); there were notable rate differences between males and females in both age groups.[13]

Four additional recent studies have focused on legislation issues at the state level. Keenan and Bratton compared injury outcome and helmet use in a regulated state (Pennsylvania) and in an unregulated state (North Carolina) and found that, despite age restrictions and helmet requirements, young people in Pennsylvania suffered serious morbidity and mortality.[14] Beidler and colleagues observed no significant changes in ATV riding patterns and little change in morbidity and mortality when comparing pre-legislation (December 1, 2004, to May 1, 2005) with post-legislation (December 1, 2005, to May 1, 2006) injury data in North Carolina.[15] Winfield and colleagues' review of university-based level-one trauma center data concluded that Florida's

ATV laws mandating helmet use for people aged <16 years and the prohibition of ATV use on roadways were inadequate to prevent injuries and their sequelae.[16] However, Stolz et al., through a statewide telephone survey in Ohio (a state with restricted licensure, training, and operation requirements for ATVs), reported that registered voters were overwhelmingly in favor of restricting the use of ATVs by children <16 years of age, prohibiting passengers on ATVs, requiring helmets, and requiring all ATV owners and users to take a safety class.[17]

In summary, despite evidence of public support and a burgeoning problem with ATV injuries, existing studies of ATV laws are either out-of-date or difficult to generalize regarding which legislative components might be most effective in reducing risk. The purpose of this study was to calculate state-specific ATV fatality rates for the period 2000–2007, grouping the states according to helmet requirements and training and licensure requirements. Comparisons were made with published rates from 1990–1999.[8]

## METHODS

ATV deaths and corresponding mortality rates per 100,000 population among people aged 1–84 years for 2000–2007 were obtained from the National Center for Health Statistics' Compressed Mortality File using the Centers for Disease Control and Prevention (CDC) WONDER online database.[18] An ATV-related death, as the underlying cause, was defined according to the International Classification of Diseases, 10th revision (ICD-10) external cause of death codes V86.0–V86.9.[19] A combination of information obtained from the Specialty Vehicle Institute of America (SVIA),[20] CPSC,[21] and a systematic review of online state-specific compilations of ATV-related legislation was used to group the states. States were considered as having ATV-related legislation if the laws went into effect at any time during the 2000–2007 study period.

The following age groups were used to present the number of deaths and mortality rates for each gender: 1–14, 15–44, 45–64, and 65–84 years of age. These groups generally correspond to groups used in previous ATV rate studies.[8,12] Table cells with fewer than five deaths were suppressed and were not included, although they are subsumed in reported totals in this article.[8]

We tabulated and compared state-specific, age group, and gender-specific rates per 100,000 population. We used Poisson regression to test whether the gender-specific rates changed significantly during 2000–2007.[4]

## RESULTS

### General comparisons

As shown in Table 1, during the eight-year study period, 7,231 ATV-related deaths occurred in the U.S., representing a rate of 0.32 per 100,000 population. Eighty-six percent of the deaths were among males at a rate of 0.55 per 100,000 population, which was six times the rate for females (0.09 per 100,000 population). Rates increased significantly among males, from 0.45 per 100,000 population in 2000 to 0.64 per 100,000 population in 2007 (slope = 0.05, $p<0.0001$); rates also increased among females, from 0.07 per 100,000 population in 2000 to 0.10 per 100,000 population in 2007 (slope = 0.06, $p<0.0001$), but at a much slower pace than for males (data not shown). Rates among females were highest in the 1- to 14-year age group (0.13 per 100,000 population) and steadily decreased with each subsequent age group. Six of every 10 male deaths occurred in the 15- to 44-year age group at a rate of 0.74 per 100,000 population, the highest rate for any age group. The highest state rates were observed in Alaska (2.67 per 100,000 population), West Virginia (1.63 per 100,000 population), Wyoming (1.31 per 100,000 population), and Maine (1.02 per 100,000 population) (Table 1).

### Helmet regulations

Comparisons of state, gender, and age group rates are presented in Table 1 for 32 states with some level of helmet-use requirements and 19 states (including the District of Columbia) with no helmet-use requirements. Nearly 5,300 deaths occurred in the states with helmet-use requirements, at a rate of 0.30 per 100,000 population, compared with more than 1,900 deaths in the states with no helmet-use requirements, which had a rate that was 23% higher (0.37 per 100,000 population). With the exception of the two oldest age categories in both groups, the rates were consistently higher in the no-helmet-law group. In both comparison groups, rates in males were generally 5.8 to 6.5 times those of females. West Virginia (1.63 per 100,000 population) had the highest rate among helmet-use regulated states, and Alaska (2.67 per 100,000 population) had the highest rate among states with no helmet-use regulation.

### Training and licensure requirements

Table 2 presents state, gender, and age group rates for 33 states that have some level of ATV training or licensure requirements compared with 18 states (including the District of Columbia) that have no such requirements. While the regulated group experienced about three times as many deaths ($n$=5,377) as the non-regulated group ($n$=1,854), the rates were

**Table 1. State-specific ATV-related death rates, by helmet law status: U.S., 2000–2007**

| State | Female | | | | Male | | | | Total |
|---|---|---|---|---|---|---|---|---|---|
| | *1–14 years* N *(rate)*[a] | *15–44 years* N *(rate)*[a] | *45–64 years* N *(rate)*[a] | *65–84 years* N *(rate)*[a] | *1–14 years* N *(rate)*[a] | *15–44 years* N *(rate)*[a] | *45–64 years* N *(rate)*[a] | *65–84 years* N *(rate)*[a] | N *(rate)*[a] |
| *Some level of helmet-use requirement (n=32)*[b] | | | | | | | | | |
| Arizona | 5 (0.10) | 13 (0.14) | 7 (0.13) | 5 (0.18) | 24 (0.46) | 75 (0.74) | 32 (0.65) | 11 (0.46) | 172 (0.38) |
| California | 19 (0.06) | 41 (0.07) | 13 (0.04) | NR | 35 (0.11) | 182 (0.28) | 71 (0.23) | 20 (0.17) | 385 (0.14) |
| Delaware | NR | NR | NR | NR | NR | NR | NR | NR | 6 (0.09) |
| Florida | 15 (0.12) | 26 (0.10) | 8 (0.05) | 6 (0.05) | 44 (0.34) | 187 (0.67) | 32 (0.20) | 21 (0.23) | 339 (0.25) |
| Idaho | 7 (0.57) | 7 (0.31) | NR | NR | 10 (0.77) | 32 (1.33) | 21 (1.63) | 9 (1.77) | 89 (0.81) |
| Kentucky | 12 (0.37) | 22 (0.31) | 6 (0.14) | NR | 29 (0.86) | 146 (2.06) | 62 (1.55) | 21 (1.34) | 298 (0.92) |
| Maine | NR | NR | NR | NR | 8 (0.83) | 63 (3.05) | 24 (1.71) | 5 (0.87) | 104 (1.02) |
| Maryland | NR | NR | NR | NR | 12 (0.26) | 39 (0.42) | 6 (0.11) | NR | 62 (0.14) |
| Massachusetts | NR | NR | NR | NR | 6 (0.12) | 39 (0.35) | 7 (0.11) | NR | 57 (0.11) |
| Michigan | 14 (0.17) | 31 (0.18) | 6 (0.06) | NR | 23 (0.27) | 214 (1.25) | 60 (0.62) | 15 (0.40) | 364 (0.46) |
| Minnesota | 10 (0.25) | 16 (0.19) | NR | NR | 18 (0.42) | 158 (1.78) | 55 (1.13) | 24 (1.31) | 285 (0.72) |
| Missouri | 10 (0.22) | 14 (0.15) | 6 (0.10) | NR | 17 (0.35) | 81 (0.84) | 25 (0.46) | 25 (1.09) | 179 (0.40) |
| Montana | NR | NR | NR | NR | 8 (1.08) | 20 (1.33) | 14 (1.40) | 14 (3.48) | 60 (0.83) |
| Nevada | NR | 6 (0.16) | NR | NR | 6 (0.30) | 28 (0.68) | 7 (0.32) | NR | 53 (0.29) |
| New Hampshire | NR | NR | NR | NR | NR | 24 (1.12) | 5 (0.37) | NR | 37 (0.37) |
| New Jersey | NR | NR | NR | NR | NR | 38 (0.26) | 5 (0.06) | NR | 50 (0.07) |
| New Mexico | NR | 6 (0.19) | NR | NR | 12 (0.72) | 23 (0.72) | 5 (0.29) | NR | 52 (0.35) |
| New York | NR | 18 (0.05) | 7 (0.04) | NR | 17 (0.11) | 185 (0.56) | 37 (0.21) | 8 (0.11) | 280 (0.19) |
| North Carolina | 11 (0.16) | 11 (0.08) | NR | NR | 41 (0.58) | 113 (0.76) | 30 (0.38) | 18 (0.58) | 230 (0.34) |
| North Dakota | NR | NR | NR | NR | 7 (1.41) | 20 (1.79) | 8 (1.30) | NR | 41 (0.83) |
| Ohio | 12 (0.13) | 16 (0.08) | 6 (0.05) | NR | 26 (0.27) | 126 (0.66) | 36 (0.33) | 9 (0.20) | 232 (0.26) |
| Oklahoma | NR | NR | NR | NR | 22 (0.73) | 44 (0.73) | 10 (0.31) | NR | 89 (0.32) |
| Oregon | NR | 7 (0.12) | NR | NR | 8 (0.28) | 48 (0.79) | 17 (0.47) | 10 (0.71) | 96 (0.34) |
| Pennsylvania | 6 (0.07) | 15 (0.08) | NR | NR | 28 (0.29) | 163 (0.81) | 40 (0.33) | 14 (0.25) | 271 (0.28) |
| Rhode Island | NR | NR | NR | NR | NR | NR | NR | NR | 6 (0.07) |
| Tennessee | 10 (0.22) | 13 (0.13) | NR | NR | 26 (0.54) | 89 (0.89) | 32 (0.56) | 20 (0.90) | 194 (0.42) |
| Texas | 30 (0.15) | 35 (0.09) | 7 (0.04) | NR | 72 (0.34) | 174 (0.42) | 52 (0.27) | 19 (0.28) | 392 (0.22) |
| Utah | NR | 6 (0.14) | NR | NR | 9 (0.34) | 44 (0.95) | 10 (0.56) | 8 (1.19) | 85 (0.44) |
| Virginia | NR | 7 (0.05) | NR | NR | 19 (0.31) | 62 (0.47) | 25 (0.35) | 6 (0.23) | 123 (0.21) |
| Washington | NR | 7 (0.07) | NR | NR | 9 (0.18) | 66 (0.61) | 24 (0.39) | 11 (0.51) | 122 (0.25) |
| West Virginia | 5 (0.40) | 17 (0.59) | 6 (0.30) | NR | 16 (1.21) | 122 (4.21) | 45 (2.35) | 20 (2.38) | 231 (1.63) |
| Wisconsin | 5 (0.12) | 15 (0.16) | 8 (0.15) | NR | 23 (0.51) | 190 (2.00) | 52 (0.97) | 16 (0.74) | 310 (0.72) |
| Total[c] | 198 (0.11) | 370 (0.10) | 113 (0.05) | 35 (0.03) | 585 (0.31) | 2,801 (0.72) | 852 (0.41) | 340 (0.40) | 5,294 (0.30) |
| By gender only | 716 (0.08) | | | | 4,578 (0.52) | | | | |

*continued on p. 368*

**Table 1 (continued). State-specific ATV-related death rates, by helmet law status: U.S., 2000–2007**

| State | Female | | | | Male | | | | Total |
|---|---|---|---|---|---|---|---|---|---|
| | *1–14 years* N *(rate)*[a] | *15–44 years* N *(rate)*[a] | *45–64 years* N *(rate)*[a] | *65–84 years* N *(rate)*[a] | *1–14 years* N *(rate)*[a] | *15–44 years* N *(rate)*[a] | *45–64 years* N *(rate)*[a] | *65–84 years* N *(rate)*[a] | N *(rate)*[a] |
| *No helmet-use laws (n=19)* | | | | | | | | | |
| Alabama | 8 (0.22) | 8 (0.11) | NR | NR | 26 (0.69) | 78 (1.04) | 18 (0.42) | 5 (0.28) | 143 (0.40) |
| Alaska | 5 (0.84) | 6 (0.53) | NR | NR | 7 (1.11) | 86 (6.88) | 23 (3.40) | 8 (5.43) | 139 (2.67) |
| Arkansas | 9 (0.41) | 13 (0.29) | NR | NR | 16 (0.69) | 77 (1.69) | 21 (0.82) | 10 (0.87) | 148 (0.69) |
| Colorado | 7 (0.19) | 9 (0.11) | 5 (0.11) | NR | 16 (0.41) | 42 (0.49) | 18 (0.41) | 10 (0.71) | 108 (0.30) |
| Connecticut | NR | 5 (0.09) | NR | NR | NR | 19 (0.33) | 5 (0.15) | NR | 30 (0.11) |
| District of Columbia | NR | NR | NR | NR | NR | NR | NR | NR | NR |
| Georgia | 12 (0.16) | 22 (0.14) | NR | NR | 34 (0.42) | 102 (0.63) | 23 (0.29) | 13 (0.51) | 209 (0.30) |
| Hawaii | NR | NR | NR | NR | NR | 8 (0.36) | NR | NR | 14 (0.14) |
| Illinois | 10 (0.10) | 14 (0.06) | NR | NR | 15 (0.14) | 128 (0.57) | 36 (0.31) | 13 (0.29) | 221 (0.22) |
| Indiana | 5 (0.10) | 14 (0.13) | NR | NR | 13 (0.24) | 78 (0.73) | 19 (0.33) | NR | 133 (0.27) |
| Iowa | 7 (0.30) | 9 (0.19) | NR | NR | 9 (0.37) | 44 (0.90) | 27 (0.95) | 10 (0.79) | 108 (0.47) |
| Kansas | 6 (0.27) | 6 (0.13) | NR | NR | 8 (0.34) | 37 (0.79) | 13 (0.51) | NR | 74 (0.35) |
| Louisiana | 10 (0.27) | 9 (0.12) | NR | NR | 34 (0.87) | 67 (0.89) | 15 (0.37) | 14 (0.90) | 150 (0.43) |
| Mississippi | 14 (0.56) | 11 (0.22) | NR | NR | 26 (1.00) | 62 (1.28) | 15 (0.58) | 18 (1.75) | 153 (0.68) |
| Nebraska | NR | NR | NR | NR | 6 (0.40) | 19 (0.64) | 9 (0.56) | 10 (1.45) | 52 (0.38) |
| South Carolina | 13 (0.39) | NR | NR | NR | 22 (0.63) | 55 (0.77) | 12 (0.30) | NR | 110 (0.33) |
| South Dakota | NR | NR | NR | NR | 12 (1.81) | 12 (0.92) | 12 (1.63) | 10 (3.02) | 56 (0.93) |
| Vermont | NR | NR | NR | NR | NR | 27 (2.66) | NR | NR | 36 (0.74) |
| Wyoming | 5 (1.28) | NR | NR | NR | NR | 17 (1.98) | 15 (2.77) | 8 (4.07) | 52 (1.31) |
| Total[c] | 118 (0.22) | 141 (0.12) | 31 (0.05) | 10 (0.03) | 250 (0.44) | 959 (0.83) | 286 (0.46) | 142 (0.60) | 1,937 (0.37) |
| By gender only | | 300 (0.11) | | | | 1,637 (0.64) | | | |
| Total U.S.[c] | 316 (0.13) | 511 (0.10) | 144 (0.05) | 45 (0.03) | 835 (0.34) | 3,760 (0.74) | 1,138 (0.42) | 482 (0.44) | 7,231 (0.32) |
| By gender only | | 1,016 (0.09) | | | | 6,215 (0.55) | | | |

[a]Rate per 100,000 population

[b]Different groups within states included users younger than 16 years of age, users operating ATVs on public land/state parks, all users, and users younger than 18 years of age.

[c]Totals account for cells that are not reportable.

ATV = all-terrain vehicle

NR = not reportable

**Table 2. State-specific ATV-related death rates, by training and licensure requirements: U.S., 2000–2007**

| State | Female | | | | Male | | | | Total |
|---|---|---|---|---|---|---|---|---|---|
| | *1–14 years* N *(rate)*[a] | *15–44 years* N *(rate)*[a] | *45–64 years* N *(rate)*[a] | *65–84 years* N *(rate)*[a] | *1–14 years* N *(rate)*[a] | *15–44 years* N *(rate)*[a] | *45–64 years* N *(rate)*[a] | *65–84 years* N *(rate)*[a] | N *(rate)*[a] |
| *Some level of training or licensure requirement* (n=*33*)[b] | | | | | | | | | |
| Arizona | 5 (0.10) | 13 (0.14) | 7 (0.13) | 5 (0.18) | 24 (0.46) | 75 (0.74) | 32 (0.65) | 11 (0.46) | 172 (0.38) |
| California | 19 (0.06) | 41 (0.07) | 13 (0.04) | NR | 35 (0.11) | 182 (0.28) | 71 (0.23) | 20 (0.17) | 385 (0.14) |
| Connecticut | NR | 5 (0.09) | NR | NR | NR | 19 (0.33) | 5 (0.15) | NR | 30 (0.11) |
| )Delaware | NR | NR | NR | NR | NR | NR | NR | NR | 6 (0.09) |
| Florida | 15 (0.12) | 26 (0.10) | 8 (0.05) | 6 (0.05) | 44 (0.34) | 187 (0.67) | 32 (0.20) | 21 (0.23) | 339 (0.25) |
| Indiana | 5 (0.10) | 14 (0.13) | NR | NR | 13 (0.24) | 78 (0.73) | 19 (0.33) | NR | 133 (0.27) |
| Iowa | 7 (0.30) | 9 (0.19) | NR | NR | 9 (0.37) | 44 (0.90) | 27 (0.95) | 10 (0.79) | 108 (0.47) |
| Kentucky | 12 (0.37) | 22 (0.31) | 6 (0.14) | NR | 29 (0.86) | 146 (2.06) | 62 (1.55) | 21 (1.34) | 298 (0.92) |
| Louisiana | 10 (0.27) | 9 (0.12) | NR | NR | 34 (0.87) | 67 (0.89) | 15 (0.37) | 14 (0.90) | 150 (0.43) |
| Maine | NR | NR | NR | NR | 8 (0.83) | 63 (3.05) | 24 (1.71) | 5 (0.87) | 104 (1.02) |
| Maryland | NR | NR | NR | NR | 12 (0.26) | 39 (0.42) | 6 (0.11) | NR | 62 (0.14) |
| Massachusetts | NR | NR | NR | NR | 6 (0.12) | 39 (0.35) | 7 (0.11) | NR | 57 (0.11) |
| Michigan | 14 (0.17) | 31 (0.18) | 6 (0.06) | NR | 23 (0.27) | 214 (1.25) | 60 (0.62) | 15 (0.40) | 364 (0.46) |
| Minnesota | 10 (0.25) | 16 (0.19) | NR | NR | 18 (0.42) | 158 (1.78) | 55 (1.13) | 24 (1.31) | 285 (0.72) |
| Missouri | 10 (0.22) | 14 (0.15) | 6 (0.10) | NR | 17 (0.35) | 81 (0.84) | 25 (0.46) | 25 (1.09) | 179 (0.40) |
| Montana | NR | NR | NR | NR | 8 (1.08) | 20 (1.33) | 14 (1.40) | 14 (3.48) | 60 (0.83) |
| Nebraska | NR | NR | NR | NR | 6 (0.40) | 19 (0.64) | 9 (0.56) | 10 (1.45) | 52 (0.38) |
| New Hampshire | NR | NR | NR | NR | NR | 24 (1.12) | 5 (0.37) | NR | 37 (0.37) |
| New Jersey | NR | NR | NR | NR | NR | 38 (0.26) | 5 (0.06) | NR | 50 (0.07) |
| New Mexico | NR | 6 (0.19) | NR | NR | 12 (0.72) | 23 (0.72) | 5 (0.29) | NR | 52 (0.35) |
| New York | NR | 18 (0.05) | 7 (0.04) | NR | 17 (0.11) | 185 (0.56) | 37 (0.21) | 8 (0.11) | 280 (0.19) |
| North Carolina | 11 (0.16) | 11 (0.08) | NR | NR | 41 (0.58) | 113 (0.76) | 30 (0.38) | 18 (0.58) | 230 (0.34) |
| North Dakota | NR | NR | NR | NR | 7 (1.41) | 20 (1.79) | 8 (1.30) | NR | 41 (0.83) |
| Ohio | 12 (0.13) | 16 (0.08) | 6 (0.05) | NR | 26 (0.27) | 126 (0.66) | 36 (0.33) | 9 (0.20) | 232 (0.26) |
| Oregon | NR | 7 (0.12) | NR | NR | 8 (0.28) | 48 (0.79) | 17 (0.47) | 10 (0.71) | 96 (0.34) |
| Pennsylvania | 6 (0.07) | 15 (0.08) | NR | NR | 28 (0.29) | 163 (0.81) | 40 (0.33) | 14 (0.25) | 271 (0.28) |
| South Dakota | NR | NR | NR | NR | 12 (1.81) | 12 (0.92) | 12 (1.63) | 10 (3.02) | 56 (0.93) |
| Tennessee | 10 (0.22) | 13 (0.13) | NR | NR | 26 (0.54) | 89 (0.89) | 32 (0.56) | 20 (0.90) | 194 (0.42) |
| Texas | 30 (0.15) | 35 (0.09) | 7 (0.04) | NR | 72 (0.34) | 174 (0.42) | 52 (0.27) | 19 (0.28) | 392 (0.22) |
| Utah | NR | 6 (0.14) | NR | NR | 9 (0.34) | 44 (0.95) | 10 (0.56) | 8 (1.19) | 85 (0.44) |
| Vermont | NR | NR | NR | NR | NR | 27 (2.66) | NR | NR | 36 (0.74) |
| West Virginia | 5 (0.40) | 17 (0.59) | 6 (0.30) | NR | 16 (1.21) | 122 (4.21) | 45 (2.35) | 20 (2.38) | 231 (1.63) |
| Wisconsin | 5 (0.12) | 15 (0.16) | 8 (0.15) | NR | 23 (0.51) | 190 (2.00) | 52 (0.97) | 16 (0.74) | 310 (0.72) |
| Total[c] | 212 (0.12) | 383 (0.10) | 112 (0.05) | 36 (0.03) | 593 (0.31) | 2,833 (0.73) | 852 (0.41) | 356 (0.42) | 5,377 (0.31) |
| By gender only | 743 (0.08) | | | | 4,634 (0.53) | | | | |

*continued on p. 370*

**Table 2 (continued). State-specific ATV-related death rates, by training and licensure requirements: U.S., 2000–2007**

| State | Female | | | | Male | | | | Total |
|---|---|---|---|---|---|---|---|---|---|
| | *1–14 years* N *(rate)*[a] | *15–44 years* N *(rate)*[a] | *45–64 years* N *(rate)*[a] | *65–84 years* N *(rate)*[a] | *1–14 years* N *(rate)*[a] | *15–44 years* N *(rate)*[a] | *45–64 years* N *(rate)*[a] | *65–84 years* N *(rate)*[a] | N *(rate)*[a] |
| *No training or licensure requirement (n=18)* | | | | | | | | | |
| Alabama | 8 (0.22) | 8 (0.11) | NR | NR | 26 (0.69) | 78 (1.04) | 18 (0.42) | 5 (0.28) | 143 (0.40) |
| Alaska | 5 (0.84) | 6 (0.53) | NR | NR | 7 (1.11) | 86 (6.88) | 23 (3.40) | 8 (5.43) | 139 (2.67) |
| Arkansas | 9 (0.41) | 13 (0.29) | NR | NR | 16 (0.69) | 77 (1.69) | 21 (0.82) | 10 (0.87) | 148 (0.69) |
| Colorado | 7 (0.19) | 9 (0.11) | 5 (0.11) | NR | 16 (0.41) | 42 (0.49) | 18 (0.41) | 10 (0.71) | 108 (0.30) |
| District of Columbia | NR | NR | NR | NR | NR | NR | NR | NR | NR |
| Georgia | 12 (0.16) | 22 (0.14) | NR | NR | 34 (0.42) | 102 (0.63) | 23 (0.29) | 13 (0.51) | 209 (0.30) |
| Hawaii | NR | NR | NR | NR | NR | 8 (0.36) | NR | NR | 14 (0.14) |
| Idaho | 7 (0.57) | 7 (0.31) | NR | NR | 10 (0.77) | 32 (1.33) | 21 (1.63) | 9 (1.77) | 89 (0.81) |
| Illinois | 10 (0.10) | 14 (0.06) | NR | NR | 15 (0.14) | 128 (0.57) | 36 (0.31) | 13 (0.29) | 221 (0.22) |
| Kansas | 6 (0.27) | 6 (0.13) | NR | NR | 8 (0.34) | 37 (0.79) | 13 (0.51) | NR | 74 (0.35) |
| Mississippi | 14 (0.56) | 11 (0.22) | NR | NR | 26 (1.00) | 62 (1.28) | 15 (0.58) | 18 (1.75) | 153 (0.68) |
| Nevada | NR | 6 (0.16) | NR | NR | 6 (0.30) | 28 (0.68) | 7 (0.32) | NR | 53 (0.29) |
| Oklahoma | NR | NR | NR | NR | 22 (0.73) | 44 (0.73) | 10 (0.31) | NR | 89 (0.32) |
| Rhode Island | NR | NR | NR | NR | NR | NR | NR | NR | 6 (0.07) |
| South Carolina | 13 (0.39) | NR | NR | NR | 22 (0.63) | 55 (0.77) | 12 (0.30) | NR | 110 (0.33) |
| Virginia | NR | 7 (0.05) | NR | NR | 19 (0.31) | 62 (0.47) | 25 (0.35) | 6 (0.23) | 123 (0.21) |
| Washington | NR | 7 (0.07) | NR | NR | 9 (0.18) | 66 (0.61) | 24 (0.39) | 11 (0.51) | 122 (0.25) |
| Wyoming | 5 (1.28) | NR | NR | NR | NR | 17 (1.98) | 15 (2.77) | 8 (4.07) | 52 (1.31) |
| Total[c] | 104 (0.19) | 128 (0.11) | 32 (0.05) | 9 (0.03) | 242 (0.42) | 927 (0.78) | 286 (0.45) | 126 (0.52) | 1,854 (0.35) |
| By gender only | | 273 (0.10) | | | | 1,581 (0.60) | | | |
| Total U.S. | 316 (0.13) | 511 (0.10) | 144 (0.05) | 45 (0.03) | 835 (0.34) | 3,760 (0.74) | 1,138 (0.42) | 482 (0.44) | 7,231 (0.32) |
| By gender only | | 1,016 (0.09) | | | | 6,215 (0.55) | | | |

[a]Rate per 100,000 population

[b]Different groups within states included users younger than 16 years of age, users younger than 18 years of age, users on public land, and users on land with other restrictions.

[c]Totals account for cells that are not reportable.

ATV = all-terrain vehicle

NR = not reportable

somewhat similar (0.31 and 0.35 per 100,000 population, respectively). There was a more noticeable difference in rates among males overall between the groups: 0.53 per 100,000 population in the regulated group and 0.60 per 100,000 population in the non-regulated group. Rate differences were also apparent in each of the male age groups.

**ATV-related deaths in 1990–1999 vs. 2000–2007**

Table 3 provides data comparing rates for 1990–1999[8] and 2000–2007. Both the number (2,226 vs. 7,231) and rate (0.09 vs. 0.32 per 100,000 population) of ATV-related deaths increased more than threefold between the two time periods. This increase was also apparent for the rate in males, which rose 3.4-fold, from 0.16 to 0.55 per 100,000 population between the two time periods. Among females, the rate differential was a 4.5-fold increase, from 0.02 to 0.09 per 100,000 population. Although the age group composition was not exactly the same for the two time periods, substantial rate increases were observed in all but one age group from the earlier to the more recent period. The exception was among the oldest male group (65–84 years of age), in which the rate decreased about 50%, from 0.80 to 0.44 per 100,000 population. While the different regulation groups were not directly comparable across the two time periods, rates were consistently higher during the most recent period.

## DISCUSSION

The results of our study show a very troubling threefold increase in the number of ATV-related deaths and the tripling of fatality rates overall in the U.S. during the two time periods studied. Significant increases were demonstrated for both genders and within every state in the U.S. between 1990 and 2000. The popularity of ATVs has increased dramatically during this time period, with 1.8 million four-wheelers in use in 1990, rising to 4.2 million in 2000 and 9.5 million in 2007.[1] Increased availability is likely a contributing factor to the substantial rise in ATV-related injury rates demonstrated in our study, along with the increasing size and power of the vehicles.[22] Alaska and West Virginia still have the highest overall rates of fatal injury, and being a male between the ages of 15 and 44 years is a risk factor for injury and death.

Coding changes may also contribute to the increased number of deaths between the two decades. Prior to 1999, ATV-related deaths were often defined by ICD Ninth Revision, Clinical Modification (ICD-9 CM) codes with the E821 series (i.e., nontraffic accident involving other off-road vehicle),[2] which provided no ATV specificity and likely underreported the true number of ATV-related deaths. Since 1999, however, ICD-10 has provided a new external cause of death code (V86: occupant of a special all-terrain or other motor vehicle designed primarily for off-road use) that groups all ATV-related fatalities under a single code and likely facilitates a more accurate counting of ATV-related deaths.[19,23]

The comparisons examining the impact of two main components of safety regulations, helmet use and training mandates, were of interest. ATV-related death rates were 23% higher in states without helmet-use requirements. This statistic suggests that helmet laws may have the desired effect of reducing the quantity and severity of injuries. Bowman and colleagues reported that helmet use appears to substantially decrease the mortality and morbidity associated with ATV-related crashes and resulting traumatic brain injuries and injuries to the head, face, and neck areas. They further stated that, "Helmet use is abysmally low among current ATV users and that enforceable state-level policy to promote increased helmet use appears to be not only warranted but critical to significantly reduce the burden of ATV-related injuries."[24]

Training requirements were not associated with a marked difference in death rates, although some high-risk subsets (i.e., males) did show lower rates in states with training requirements. There is evidence from some states with such laws in place that enforcement is low and compliance with the requirements is highly variable. Further, the training requirements range widely from a few questions on a driving test to hands-on training. While the effectiveness of hands-on training to prevent ATV injury has not been thoroughly studied, more experience on the vehicles and a clearer understanding of the principles of riding an ATV would seem prudent for any novice rider. Unfortunately, the ATV Safety Institute, which provides much of the hands-on ATV training in the U.S., does not release data about the training it provides. Therefore, we relied on the broader approach of comparing states with or without legislative training requirements rather than comparing states where actual hands-on training has occurred.

Some policies that have shown considerable success in motor vehicle injury reduction have yet to be attempted for ATV use. For example, a graduated driver license approach for ATV operators might be considered an option that would allow young operators to develop skills on ATVs gradually and in lower-risk environments. This approach would require a carefully designed study to demonstrate its impact.

**Table 3. Comparison of ATV fatalities and rates: U.S., 1990–1999[a] and 2000–2007**

| *Characteristics* | *1990–1999* N *(rate)*[b] | *2000–2007* N *(rate)*[b] |
|---|---|---|
| Gender | | |
| Male | 1,935 (0.16) | 6,215 (0.55) |
| Female | 291 (0.02) | 1,016 (0.09) |
| Age (in years) | | |
| Males | | |
| 1–16 | 657 (0.21) | NA |
| 1–14 | NA | 835 (0.34) |
| 17–49 | 1,052 (0.16) | NA |
| 15–44 | NA | 3,760 (0.74) |
| 50–64 | 126 (0.07) | NA |
| 45–64 | NA | 1,138 (0.42) |
| 65–84 | 100 (0.80) | 482 (0.44) |
| Females | | |
| 1–16 | 138 (0.05) | NA |
| 1–14 | NA | 316 (0.13) |
| 17–49 | 133 (0.02) | NA |
| 15–44 | NA | 511 (0.10) |
| 50–64 | 11 (0.01) | NA |
| 45–64 | NA | 144 (0.05) |
| 65–84 | 9 (0.01) | 45 (0.03) |
| Helmet and other safety equipment (21 states) | 1,180 (0.08) | NA |
| Helmet requirement | | |
| Yes (32 states) | NA | 5,294 (0.30) |
| No (19 states and Washington, DC) | NA | 1,937 (0.37) |
| Machine-related requirements (23 states) | 694 (0.09) | NA |
| No safety legislation (six states and Washington, DC) | 352 (0.17) | NA |
| Training and/or licensure requirement | | |
| Yes (33 states) | NA | 5,377 (0.31) |
| No (18 states and Washington, DC) | NA | 1,854 (0.35) |
| U.S. totals | 2,226 (0.09) | 7,231 (0.32) |

[a]Source: Helmkamp JC. A comparison of state-specific all-terrain vehicle-related death rates, 1990–1999. Am J Public Health 2001;91:1792-5.

[b]Rate per 100,000 population

ATV = all-terrain vehicle

NA = not applicable

DC = District of Columbia

**Limitations**

This study was subject to several limitations. One limitation was that categorizing ATV laws across states is challenging. We could identify no two states with the same combination of policies governing ATVs in place in either 2000 or 2007.[20] There was also variability even among those states with helmet-use and training requirements as to the age groups and circumstances of use under which the law applies. In 2000, SVIA reported that nine states had ATV laws addressing helmet use, three states had laws addressing training, and 13 other states had laws addressing both components.[20] Legislation addressing helmet use and training was in effect for both California and Texas during the entire eight-year study period, while North Carolina—also in this same group—had both helmet-use and training components that became effective only during the latter part of the study period. ATV-related death rates in these three states all increased substantially during the decade: in California, from 0.04 to 0.14 per 100,000 population; in Texas, from 0.05 to 0.22 per 100,000 population; and in North Carolina, from 0.13 to 0.34 per 100,000 population. While we chose to group these states together regardless of when their legislation became effective during the study period, we acknowledge that misclassification of the status of these laws during the study period could have affected the results. We do, however, feel that our broad groupings were appropriate and help explain the notable rate differences observed between 1990–1999 and 2000–2007, and

suggest that there may be an association between ATV laws and fatality rates. Rodgers opined in his study of ATV mortality rates from 1990–1999 that high mortality rates may drive legislation, which, in turn, would hopefully help facilitate rate reduction over time;[9] our results suggest that the hoped-for rate reduction has not yet occurred.

In a descriptive study such as this, the potential for misclassification exists in terms of the status of the laws and how the states were grouped. Longer exposure to policies may lead to increased awareness, adoption of behavior change, and better enforcement of the laws. In a recent study assessing rural ATV riders' preferences for safety messaging, Brann and colleagues concluded that, while licensing and training requirements are generally lacking, they are considered desirable in the promotion of ATV safety by the ATV users participating in the focus groups.[25]

Finally, we recognize that other unmeasured factors (e.g., mix of users, types of vehicles used in different parts of the country, and law enforcement) may contribute to the rate patterns that were found. Winfield and colleagues provide a useful framework for ATV policy, suggesting that there are inherent flaws in a legislation-dominated approach to ATV safety—compliance (which is dependent on an individual's behavior), enforcement (which is dependent on having sufficient resources as well as a physical presence of those who can enforce), and an infinite number of independent variables (which can only be covered by the most restrictive of laws [i.e., an absolute ban]) that potentially would have a greater impact on injuries than does the presence of the laws themselves.[16]

## CONCLUSIONS

Our data suggest that helmet-use regulations may influence the rate of ATV-related deaths, making an increased emphasis on the importance of helmet use while using ATVs an important strategy in reducing these injuries. Training requirements were not as clearly associated with a reduction in deaths, and further study of the type and amount of training required to make a difference is needed. Finally, for any policy to be effective, it must be enforced, and further study of barriers to acceptance and enforcement of these laws is needed.

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# The Predictive Value of Self-Report Questions in a Clinical Decision Rule for Pediatric Lead Poisoning Screening

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## ABSTRACT

**Objective.** We derived a clinical decision rule for determining which young children need testing for lead poisoning. We developed an equation that combines lead exposure self-report questions with the child's census-block housing and socioeconomic characteristics, personal demographic characteristics, and Medicaid status. This equation better predicts elevated blood lead level (EBLL) than one using ZIP code and Medicaid status.

**Methods.** A survey regarding potential lead exposure was administered from October 2001 to January 2003 to Michigan parents at pediatric clinics ($n$=3,396). These self-report survey data were linked to a statewide clinical registry of blood lead level (BLL) tests. Sensitivity and specificity were calculated and then used to estimate the cost-effectiveness of the equation.

**Results.** The census-block group prediction equation explained 18.1% of the variance in BLLs. Replacing block group characteristics with the self-report questions and dichotomized ZIP code risk explained only 12.6% of the variance. Adding three self-report questions to the census-block group model increased the variance explained to 19.9% and increased specificity with no loss in sensitivity in detecting EBLLs of ≥10 micrograms per deciliter.

**Conclusions.** Relying solely on self-reports of lead exposure predicted BLL less effectively than the block group model. However, adding three of 13 self-report questions to our clinical decision rule significantly improved prediction of which children require a BLL test. Using the equation as the clinical decision rule would annually eliminate more than 7,200 unnecessary tests in Michigan and save more than $220,000.

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The purpose of testing for elevated blood lead levels (EBLLs) in children is to identify cases that would require appropriate treatment and/or environmental intervention. The 1989 Centers for Medicare & Medicaid Services requirement to test all children enrolled in Medicaid is costly and requires extensive outreach.[1] It also created a need for clinical practice guidelines and decision rules to determine which young children are at high enough risk to require testing for lead poisoning.

In 1997, the Centers for Disease Control and Prevention (CDC)[2,3] developed such clinical practice guidelines and defined high risk of symptoms of lead poisoning as having a blood lead level (BLL) of ≥10 micrograms per deciliter (μg/dL).[4] CDC encouraged state health departments to develop plans to identify all children at high risk of lead poisoning based on local data concerning BLLs and selected risk factors.

The CDC guidelines were based on several criteria, including age of housing and percentage of population with incomes below the federal poverty level (FPL) in the ZIP code in which the child resides. As part of its targeting, CDC also recommended using information obtained from five self-report questions on lead exposure (Figure).[3] The Michigan Department of Community Health (MDCH) replaced question #5 with the following question: "Does the child's family use any home remedies that may contain lead?" and provided a list of such remedies. At the time, MDCH followed Medicaid rules requiring that all children enrolled in Medicaid be tested, although not all such children were actually tested. In addition, CDC and MDCH recommended that a child be tested if the child's caregiver answered "yes" or "I don't know" to any of the self-report questions, or if the child was Medicaid-enrolled or lived in a high-BLL-risk ZIP code.

While these self-report questions have been widely used, studies have not found them to be good predictors of EBLL.[5–8] Moreover, some of these questions are poorly worded and may not be understood by respondents. Therefore, there is a need to both improve the wording of these questions and assess the predictive validity of the improved questions.

Previous research in Michigan[9] and elsewhere[10,11] has led to a refined geographic approach to predicting the BLL of children. Unlike previous studies that use ZIP codes and census tracts, this research relied heavily on the characteristics of the census-block group (the smallest geographic unit for which detailed data were available). In Michigan, census-block groups explained substantially more variance in BLL than census tracts or ZIP codes. This method yielded a prediction equation with better sensitivity and specificity than ZIP code and Medicaid status, which would have identified more high-risk children, while saving more than $150,000 during the four-year period 2002–2005.[9]

This equation, derived from our previous work,[9] predicted BLL from a weighted linear combination of the following characteristics of the census-block group in which the child lived: percentage of housing built before 1940 (HSNG_PRE1940), percentage of housing built during 1940–1949 (HSNG_1940-49), percentage of population with income <185% FPL (INC_185%_POV), percentage who did not graduate from high school (HS_DROPOUT), percentage black, and percentage Latino; as well as the following characteristics of the child: Medicaid status, race/ethnicity (BLACK_CHILD or not), age, and year tested.

The optimal prediction equation for 2002–2005 was $Ln(\text{BLL} - 0.5) = -0.487 + 0.694 \times \text{HSNG\_PRE1940} + 0.0119 \times \text{HSNG\_1940-49} + 0.212 \times \text{INC\_185\%\_POV}$

**Figure. CDC and MDCH recommended screening questions for pediatric lead poisoning**

| *Question number/ source* | *Question* |
|---|---|
| 1. CDC/MDCH | Does the child now, or in the recent past, live in or often visit a house built before 1950 with peeling or chipping paint? This could include a day care, preschool, or home of a relative. |
| 2. CDC/MDCH | Does the child now, or in the recent past, live in or often visit a house, built before 1978, that has been remodeled within the last year? |
| 3. CDC/MDCH | Does the child have a brother or sister (or playmate) with lead poisoning? |
| 4. CDC/MDCH | Does the child live with an adult whose job or hobby involves lead? (list of jobs/hobbies provided) |
| 5. CDC | Does the child live near an active lead smelter, battery recycling plant, or other industry likely to release lead? |
| 5. MDCH | Does the child's family use any home remedies that may contain lead? (A list of remedies was provided. MDCH's list at the time survey data were gathered contained 19 substances. Of these, nine substances were also on CDC's current list. The current CDC list also contains seven home remedies not on that MDCH list.) |

CDC = Centers for Disease Control and Prevention

MDCH = Michigan Department of Community Health

+ 0.400 × %_BLACK + 0.556 × %_LATINO + 0.206 × BLACK_CHILD + 0.172 × MEDICAID + 0.109 × MEDICAID × HSNG_PRE1940 + 0.171 × MEDICAID × HSNG_1940-49.

This prediction equation also includes coefficients of dummy variables that adjust for the child's age and year of the BLL test. Additionally, it includes empirical Bayesian residuals generated by Hierarchical Linear Modeling.[12] These residuals estimate the degree to which the prediction equation over- or underestimates the BLL in each census-block group.

While prior literature suggests that these self-report exposure questions are not adequate predictors of BLL,[5–8] it is possible that some of them are worth adding to the census-block group prediction equation. The present study expands our previous work by including modified MDCH-CDC self-report questions and other self-report questions suggested in the literature. The purpose is to create the most cost-effective method of targeting BLL testing, which can then be disseminated by public health professionals to clinicians and parents.

## METHODS

Two datasets were linked for this study. One was our survey on sources of lead exposure, which was administered from October 2001 to January 2003 to more than 4,000 parents and caregivers of young children at 36 pediatric clinics in Michigan, including 18 county health departments, two urban health systems, and 16 small clinics serving migrant workers. The survey contained questions that modified the five MDCH-CDC items, plus a question about lead smelters and questions about additional sources of lead exposure (e.g., pacifier use[5] and water that came through lead pipes).[13]

Because respondents were disproportionately of low education, the current survey modified the CDC questions by dividing sentences with several clauses or phrases into simpler sentences. It also divided some of the CDC questions into several questions. CDC question #1 in the Figure was divided into three separate questions asking (*1*) whether the residence was built before 1950, (*2*) whether it had peeling paint, and (*3*) whether the child had visited a house with peeling paint. Our questionnaire had a Flesch-Kincaid reading grade level of 4.1, whereas the original CDC questionnaire has a reading grade level of 7.8. We subsequently created variables whose meaning closely corresponded to the original CDC questions (Table 1).

We pilot-tested the survey with 15 parents to ascertain whether parents were willing to complete it and readily understood the questions. All parents completed the survey. Only one parent had any difficulty with reading the questionnaire, and clinic staff described her as barely able to read.

After piloting, the survey was administered by trained staff at participating clinics. Of those invited to complete the survey, the participation rate exceeded 90%. As an incentive, respondents were given a long-distance phone card. The survey took less than 10 minutes to complete, and respondents filled it out while waiting at the clinic.

The second dataset consisted of a clinical registry of all BLL tests in Michigan maintained by MDCH, with identifiers removed. If a child had more than one BLL test, we analyzed the highest venous result, if available, and the highest capillary result, if not available. Only 26% of the tests were venous, although 65% of the EBLLs were venous.

Of the 4,194 survey responses, 92.4% ($n$=3,876) could be linked to the child's BLL test. The final number of cases (3,396) was primarily due to cases lost from BLL records that lacked a valid address. Other cases were excluded because the child was older than 5 years of age or the age was missing.

### Methods for missing data

CDC recommended that missing data on any question regarding risks of lead exposure be treated as having answered "yes" to that question.[2] We followed this recommendation as one of our methods, with several qualifications. For example, because we asked questions about housing built before 1950 and the presence of peeling paint separately, we could have missing data on one of those questions. If the respondent answered "no" to either question, then even if there were missing data on the other question, we considered the answers tantamount to a "no" on the original CDC question #1. When using this method, we also recoded missing values of race to black, Medicaid eligibility to yes, and pacifier use to never, as these values are associated with higher BLL.

The aforementioned CDC method tends to produce biased coefficient estimates. To obtain unbiased estimates without list-wise deletion, we used 10 random imputations of missing data as an alternative method.[14] The values of the dependent variable were used to impute missing values of the independent variables.[15] The imputations were performed using SPSS® version 18.0, using the automatic imputation method.[16]

## RESULTS

The range of BLLs was 1 to 164 µg/dL. Consistent with previous findings,[9,17] BLL was normally distributed after logarithmic transformation. The transformation that

**Table 1. Descriptive statistics for key questions in a survey of BLLs[a] and items in the MDCH clinical BLL database: Michigan, October 2001–January 2003**

| Variable | Mean[b] | Nonmissing responses Percent |
|---|---|---|
| Self-report exposure questions not in MDCH clinical registry | | |
| Frequency of pacifier use | 40.5 | 98.6 |
| Adult job involves lead | 18.8 | 93.3 |
| Any house built before 1980 that has been remodeled[c] | 14.8 | 89.4 |
| Adult hobby involves lead | 13.9 | 92.9 |
| Any house with peeling paint that child regularly visits[c] | 11.8 | 98.1 |
| House built before 1950 with peeling paint inside[c] | 6.7 | 89.4 |
| House with lead pipes for water | 5.8 | 89.4 |
| Sibling with elevated BLL | 4.0 | 91.5 |
| House built before 1950 with peeling paint outside and child plays outside[c] | 3.1 | 89.4 |
| Any playmate with elevated BLL | 3.0 | 95.6 |
| Child ever lived near plant emitting lead | 1.9 | 88.8 |
| Any home remedies used that may contain lead | 0.5 | 91.8 |
| Variables in MDCH clinical BLL database | | |
| Child covered by Medicaid | 63.5 | 97.1 |
| Child is black/African American | 33.1 | 98.0 |

[a]While many of the survey questions were based on CDC questions, the exact wording was often different from the original CDC wording.

[b]All variables, except pacifier use, are dichotomous, and the mean is the percentage of those with nonmissing responses who answered affirmatively. Pacifier use is coded 0 for "never or almost never" (74.7% of respondents), 0.5 for "sometimes" (8.0% of respondents), and 1 for "daily or almost daily" (16.0% of respondents).

[c]These compound questions were each originally asked as several separate questions and the answers were then combined for data analysis.

BLL = blood lead level

MDCH = Michigan Department of Community Health

CDC = Centers for Disease Control and Prevention

minimizes both skew and heteroscedasticity of variances is $Ln(\text{BLL} - 0.5)$, where $Ln$ is the logarithm to base $e$ (≈2.718). This function was the dependent variable in all regressions. The minimum BLL recorded in the MDCH database was 1.0. Therefore, many results recorded as 1.0 might actually have been lower.

### Comparing BLLs for survey cases with the full MDCH database

We compared BLL data for the survey cases with those from the full MDCH database of tests in 2002 (the year in which 83% of the BLL tests of children of survey respondents were conducted). As shown in Table 2, the prediction equation explained a much smaller proportion of the variance in $Ln(\text{BLL} - 0.5)$ in the survey cases than in the full MDCH database. It also compared the conditional standard deviations (SDs) of the same dependent variable for the two datasets. These SDs were very similar in the two datasets, indicating that the dependent variable was predicted almost equally well[18] in both.

The survey data cases have a smaller mean for the dependent variable than does the full MDCH data. This smaller mean occurred because the survey data underrepresented some high-risk groups, such as low-income families in Detroit. Almost all of the self-report questions provided three response alternatives: "yes," "no," and "don't know." Table 1 shows response distributions.

### Regression analyses

The census-block group prediction score by itself explained 18.1% of the variance in $Ln(\text{BLL} - 0.5)$, while the self-report questions plus dichotomized ZIP code risk explained only 12.6% of the variance. Thus, the self-report questions should not replace the census-block group information.

The major research aim was to estimate how much additional predictive value the self-report variables contributed to the estimation of BLL, above that provided by the previous census-block group prediction equation. We entered the linear combination of variables from the optimal census-block group prediction equation[9] followed by the self-report variables.

For both the CDC "missing data implies risk"[2] and the multiple imputation methods, we added 13 self-report variables as predictors to the regression containing the census-block group equation. Twelve of these variables are in Table 1. The 13th variable was the product of the self-report response regarding

**Table 2. Comparison of BLL results for survey data cases from October 2001–January 2003 with full MDCH BLL database for 2002**

| *Characteristics* | *Full MDCH database* | *Survey data cases* |
|---|---|---|
| $R^2$ (block group equation) | 0.384 | 0.179 |
| Mean of dependent variable, *Ln*(BLL − 0.5) | 0.790 | 0.632 |
| SD of dependent variable | 0.984 | 0.923 |
| Conditional SD of *Ln*(BLL − 0.5) | 0.774 | 0.837 |
| SD of independent variable (census-block group prediction score from MDCH database) | 0.551 | 0.443 |
| Sample size (*N*) | 63,295 | 3,396 |

BLL = blood lead level

MDCH = Michigan Department of Community Health

SD = standard deviation

whether the child lived in a house with interior peeling paint and the proportion of housing built before 1940 in the respondent's census-block group.

For the CDC method, the adjusted $R^2$ from adding all 13 predictors was 0.192, while for random imputation it was 0.200 (data not shown). For both methods, the same three added predictors had statistically significant coefficients, while the other predictors (not shown) were nonsignificant.

The next step was to conduct a regression analysis using only the census-block group equation and the three significant predictors. As shown in Table 3, the adjusted $R^2$ values, with only these three self-report predictors, were within 0.001 of the aforementioned adjusted $R^2$ values from all 13 predictors.

To aid interpretation, we present the anti-logarithms of the regression coefficients in Table 3. For both data analysis methods, all other things being equal, daily pacifier use resulted in a predicted BLL that was 81% of the BLL of a child who did not use one. For both methods, a child living in a house with peeling paint in a census-block group in which 100% of the housing was built before 1940 had a predicted BLL that was approximately 40% higher than that of an otherwise

**Table 3. Unstandardized regression coefficients predicting *Ln*(BLL − 0.5) from census-block group prediction equation and self-report variables, assuming that missing responses are tantamount to "yes" (i.e., risk suggestive) and by multiple random imputation: Michigan, October 2001–January 2003[a]**

| | *CDC—missing implies risk* | | | *Random multiple imputation* | | |
|---|---|---|---|---|---|---|
| *Variables* | *B* | *SE* | *BLL multiplier*[b] | *B* | *SE* | *BLL multiplier*[b] |
| (Constant) | 0.041 | 0.029 | | 0.053 | 0.029 | |
| Prediction score from census-block group characteristics, race/ethnicity, Medicaid status, age, and year BLL tested | 0.811[c] | 0.034 | 2.25 | 0.802[d] | 0.034 | 2.23 |
| Sibling with elevated BLL | 0.121[d] | 0.044 | 1.13 | 0.376[c] | 0.076 | 1.46 |
| Frequency of pacifier use | −0.212[c] | 0.038 | 0.81 | −0.215[c] | 0.038 | 0.81 |
| House with peeling paint inside × percentage pre-1940 houses in block group | 0.326[c] | 0.079 | 1.39 | 0.355[c] | 0.089 | 1.43 |
| $R^2$ | 0.193 | | | 0.200 | | |
| Adjusted $R^2$ | 0.192 | | | 0.199 | | |

[a]Data on BLL and all variables contributing to the prediction score are from the Michigan Department of Community Health clinical registry. Other data are from the researchers' survey.

[b]The BLL multiplier is the anti-logarithm of the regression coefficient. It is equal to $e^B$, where $e$ is the base of natural logarithms.

[c]$p<0.001$

[d]$p<0.01$

BLL = blood lead level

CDC = Centers for Disease Control and Prevention

SE = standard error

**Table 4. Sensitivity and specificity of BLL scores[a] in predicting BLLs of ≥10 micrograms per deciliter from census-block group prediction equation and adding three best self-report exposure predictors, by two different methods: Michigan, October 2001–January 2003[b]**

| *Risk score (i.e., predicted value of* Ln*[BLL − 0.5])* | *Sensitivity* | *Specificity* | *Number of non-EBLL tests that could be avoided[c]* | *Number of EBLL cases that would be missed[d]* |
|---|---|---|---|---|
| Derived from census-block group prediction equation alone | 0.992 | 0.159 | 520 | 1 |
| *Below are results of adding three self-report exposure questions to census-block group prediction equation by alternative methods* | | | | |
| Method: CDC—missing implies risk | 0.992 | 0.206 | 673 | 1 |
| Method: random multiple imputation | 0.992 | 0.216 | 706 | 1 |

Note: Of 3,396 children, 23 had an EBLL.

[a]The score used for the census-block group prediction equation is derived from the BLL prediction equation found in: Kaplowitz SA, Perlstadt H, Post LA. Comparing lead poisoning risk assessment methods: census block group characteristics vs. zip codes as predictors. Public Health Rep 2010;125:234-45. This equation is derived from census-block group variables plus race/ethnicity, Medicaid status, and age. The risk scores for the CDC and random multiple imputation methods were derived from the regression coefficients in which the self-report variables were used as predictors in addition to the census-block group prediction equation. The testing cutoff point for these calculations is 0.3, which means that we would test only those whose risk score was at least 0.3.

[b]Data on BLL and all variables contributing to the prediction score are from the Michigan Department of Community Health clinical registry. Other data are from the researchers' survey.

[c](specificity) × (number of non-elevated tests)

[d](1 − sensitivity) × (number of elevated tests)

BLL = blood lead level

EBLL = elevated blood lead level

CDC = Centers for Disease Control and Prevention

identical child in a house without peeling paint or a census-block group with no pre-1940 housing. Using the CDC method, children who had a sibling with an EBLL had a predicted BLL that was 13% higher than that of an otherwise identical child without such a sibling. Using random imputation, children with an EBLL sibling had a predicted BLL that was 46% higher.

**Identifying the most cost-effective decision rule**

The most cost-effective decision rule would correctly identify all children with EBLLs (100% sensitivity) without misidentifying any without EBLLs (100% specificity). We compared cost-effectiveness by computing the sensitivity and specificity for three BLL prediction equations: first by using the census-block group prediction equation by itself, and then by including the three significant self-report lead questions. This comparison was made for both the CDC's missing data implies risk strategy and the multiple imputation method. While no BLL is known to be safe,[19] consistent with CDC, we defined EBLL as ≥10 µg/dL. A good clinical decision rule requires a well-constructed risk score,[20] and we used the predicted value of $Ln(\text{BLL}-0.5)$. The Centers for Medicare & Medicaid Services requirement that all children on Medicaid be tested, and the CDC guidelines calling on state health departments to develop screening plans for all children at high risk, indicate that high sensitivity, i.e., correctly identifying all children with EBLLs, is more important than high specificity. We chose 0.3 as our risk score cutoff point because this number achieves high sensitivity.

Table 4 compares the prediction methods. The sensitivity of the three methods was identical (0.992). However, adding the three self-report questions to the census block group equation gave higher specificity. Adding these questions via CDC's method would eliminate 153 (673 − 520) unnecessary tests. Adding these questions via random multiple imputation would eliminate 186 (706 − 520) unnecessary tests.

Brown and Chattopadhyay found that the average cost of a private-sector BLL venous sample test was $31, including the cost of the blood draw.[21] Adding the self-report questions would have resulted in a total savings of $31 × 153 = $4,743 for the CDC method and $31 × 186 = $5,766 for the random multiple imputation method. This analysis was based on 3,396 cases, approximately 2% of the more than 160,000 BLL tests performed each year in Michigan from 2007 to 2009. Extrapolating suggests that using the three self-report questions statewide would annually eliminate more than 7,200 unnecessary tests and save more than $220,000 using the CDC method and almost $270,000 using random multiple imputation. This savings would occur with no loss in sensitivity.

## DISCUSSION

In an effort to improve prior predictions of children's BLLs, we used a combination of survey and clinical data. Three of 13 self-report questions made statistically significant contributions to predicting BLL. These three were having a sibling with an EBLL, using a pacifier (i.e., using it more often is better), and having peeling paint inside a child's residence (when multiplied by the percentage of pre-1940 housing in the census-block group).

By comparison, the CDC-based question, "Has the child lived in a house built before 1950 with peeling paint inside?" and *not* multiplying by the census information had *no* significant predictive value, even when the interaction term involving this question was excluded from the model. This question may have had little value because parents who rent their housing often do not know when the house was built, and more than half of the respondents answering this question indicated that they rented. Similarly, the nonsignificant predictive value of the question on lead pipes may have been a result of parents not knowing whether or not their residence had such pipes.

The observed negative association between pacifier use and BLL is surprising, given that Dalton et al.[5] found a significant positive association. Their results are consistent with the assumption that if pacifiers fall on the floor and pick up lead dust, children may then inhale or ingest lead upon insertion. However, our results suggest that a pacifier may act as a barrier that prevents lead dust from entering the mouth and/or reduces the need to suck on paint chips or lead-painted toys. We also note that our sample size ($n$=3,396) was much larger than Dalton's ($n$=463) and that we estimated the effect of pacifier use on BLL while controlling for many other variables, whereas Dalton's analyses were strictly bivariate.

### Limitations

This study was subject to several limitations. For one, these data were from one state and represented a limited time period (late 2001 through early 2003). Also, the survey was not representative geographically, as the sample consisted of patients at the participating pediatric clinics in the state. Furthermore, some of the elevated capillary tests were not followed up by more accurate venous tests. Therefore, it is possible that some of the EBLL tests in the clinical records represented false-positives. Hence, we reran the analysis, eliminating elevated capillary BLL results. We found that all estimated regression coefficients were within 5% of the values presented in Table 3 and that none of our conclusions would be brought into question.

## CONCLUSIONS

Prior clinical decision rules for targeting lead testing have used the criteria of Medicaid eligibility, residing in a high-risk ZIP code, or answering "yes" or "don't know" to one of the recommended self-report questions. These rules have a much lower predictive validity than an equation that is a linear combination of census-block group characteristics and several individual characteristics.[9] As shown previously, adding the three self-report questions increased the predictive value of the census-block group equation.

CDC recently noted that since its 1997 recommendations were developed, all 42 CDC-funded childhood lead poisoning prevention programs in 37 states have developed data-driven targeted screening criteria. CDC went on to recommend that because "state and local officials are more familiar than federal agencies with local risk for elevated BLLs . . . that these officials have the flexibility to develop blood lead screening strategies that reflect local risk for elevated BLLs."[1]

Our clinical decision rule adheres to this guidance and has the potential to better target BLL testing in children, thereby reducing testing costs while simultaneously identifying more cases of EBLL. In fact, our previous research[9] shows that using a census-block group equation in Michigan, rather than ZIP codes, would have identified more cases of BLL >10 μg/dL, while saving more than $150,000 in four years.

This study shows that adding the three self-report questions to the equations increases specificity with no loss in sensitivity and should increase the monetary savings with no loss in the number of elevated cases identified.

The purpose of the prediction equation is to create a clinical decision rule that provides medical providers and public health departments with a better approach to determine which children should undergo BLL testing. Such decision rules are derived from rigorous quantitative research[22–25] and are developed for clinically important conditions that are prevalent and for which current diagnostic testing practices vary widely and are inefficient.[9,25]

While the census-block group equation has much greater predictive validity for EBLL than ZIP codes, it is fairly easy to know the ZIP code and, at first glance, using the prediction equation appears more difficult and time-consuming. However, a Web tool has been developed to perform the computations in this equation, and online access is available at http://midata.mwbc.info/bll/msu-mdch_program.htm. Clinic staff or parents can enter the child's Michigan address, Medicaid status, race/ethnicity, age, and the answers to the three self-report questions that are useful predictors.

The Web tool processes these responses using the prediction equation and returns a recommendation as to whether or not the child needs a BLL test.

Clinical decision rules similar to the one presented in this article can be developed for other states. However, it will require developing a prediction algorithm using existing statewide BLL test data and U.S. Census Bureau information. We have described the type of statistical analyses required in this article and our previous article.[9] A prediction equation would be the core of an online program that could be easily used by providers and parents alike. It would also facilitate cost-effective testing.[21–24]

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# State Health Department Perceived Utility of and Satisfaction with ArboNET, the U.S. National Arboviral Surveillance System

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## ABSTRACT

**Objectives.** We assessed the perceived utility of data collected through ArboNET, the national arboviral surveillance system, and evaluated state health department user satisfaction with system function.

**Methods.** We used an online assessment tool to collect information about types of arboviral surveillance conducted, user satisfaction with ArboNET's performance, and use of data collected by the system. Representatives of all 53 reporting jurisdictions were asked to complete the assessment during spring 2009.

**Results.** Representatives of 48 (91%) jurisdictions completed the assessment. Two-thirds of respondents were satisfied with ArboNET's overall performance. Most concerns were related to data transmission, particularly the lack of compatibility with the National Electronic Disease Surveillance System (NEDSS). Users found mosquito (85%), human disease (80%), viremic blood donor (79%), and veterinary disease (75%) surveillance data to be useful. While there was disagreement about the usefulness of avian mortality and sentinel animal surveillance, only 15% of users supported eliminating these categories. Respondents found weekly maps and tables posted on the U.S. Geological Survey (92%) and CDC (88%) websites to be the most useful reports generated from ArboNET data. Although many jurisdictions were willing to report additional clinical or laboratory data, time and resource constraints were considerations. Most respondents (71%) supported review and possible revision of the national case definition for human arboviral disease.

**Conclusions.** As a result of this assessment, CDC and partner organizations have made ArboNET NEDSS-compatible and revised national case definitions for arboviral disease. Alternative data-sharing and reporting options are also being considered. Continued evaluation of ArboNET will help ensure that it continues to be a useful tool for national arboviral disease surveillance.

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ArboNET, the national arboviral surveillance system, was developed in 2000 to monitor West Nile virus (WNV) infections in humans, mosquitoes, birds, and other animals. This comprehensive approach helped track the progression of WNV activity across the United States and improved our understanding of the epidemiology, ecology, and transmission of WNV. Since WNV was first detected in the Western Hemisphere in 1999, it has become the leading cause of arboviral encephalitis in the U.S.[1–3] The national incidence of WNV disease peaked in 2002 and 2003 and then declined;[3,4] however, focal seasonal outbreaks continue to occur, resulting in substantial morbidity and mortality and requiring significant public health response and resources. In addition to WNV, other domestic arboviruses continue to cause sporadic and seasonal outbreaks.[2] Furthermore, there is the potential for the emergence of other arboviruses, which could become established if introduced,[5] a vulnerability demonstrated by recent episodes of local dengue transmission in Texas and Florida.[6,7]

In response to changing national trends in arboviral epidemiology, ArboNET has been modified and expanded since its initial development in 2000. For example, following the identification of transfusion-associated WNV transmission in 2002,[8,9] routine screening of all blood donations for WNV was initiated in the U.S., and ArboNET was modified to include reports of WNV presumptive viremic blood donors (PVDs). Beginning in 2003, ArboNET was expanded to include all other nationally notifiable domestic arboviruses (i.e., California serogroup, eastern equine encephalitis, Powassan, St. Louis encephalitis, and Western equine encephalitis viruses) and selected travel-associated arboviruses (e.g., chikungunya, dengue, Japanese encephalitis, tick-borne encephalitis, and yellow fever viruses). Despite the expanding scope of the ArboNET system, national funding to state and local health departments to support arboviral surveillance and testing has been drastically reduced in recent years.

In 2008 and 2009, we conducted the first formal evaluation of ArboNET to determine if the current structure, function, and content provided useful information for public health decision-making, response, and research. As a component of the evaluation, we queried public health departments to assess the utility of ArboNET data and satisfaction with system function. We report the findings of this assessment and make recommendations for system improvement.

## METHODS

ArboNET is a passive electronic system managed by the Centers for Disease Control and Prevention (CDC). Arboviral surveillance data are reported to ArboNET by 50 state and three local or territorial health departments (New York City, the District of Columbia, and Puerto Rico). Reporting jurisdictions receive data from public health and commercial reference laboratories, blood-collection agencies, and health-care providers. Jurisdictions transmit data to ArboNET using one of three methods: (*1*) uploading records from an existing electronic system using an Extensible Markup Language (XML) message, (*2*) uploading from a Microsoft® Access database using an XML message, or (*3*) entering records manually using a Web-based form. ArboNET data are routinely reviewed, summarized, and disseminated through Epi-X (the Epidemic Information Exchange, CDC's secure communications network for public health professionals), the *Morbidity and Mortality Weekly Report* (*MMWR*), as well as the websites of CDC, the U.S. Geological Survey (USGS), and the Public Health Agency of Canada. In addition, researchers, pharmaceutical companies, the media, and the general public can request limited-use datasets from ArboNET.

Domestic human arboviral diseases, which are nationally notifiable conditions, are reported to ArboNET using standardized case definitions that include clinical and laboratory criteria.[10] WNV PVDs are identified through universal screening of the blood supply; case definitions and reporting practices for PVDs vary by jurisdiction and blood services agency. Data routinely collected in ArboNET for human disease cases and PVDs include patient demographics, county and state of residence, date of illness onset or blood donation, case status (i.e., confirmed, probable, suspect, or not a case), clinical syndrome (e.g., encephalitis, meningitis, or uncomplicated fever), and outcome. Cases reported as encephalitis, meningitis, or acute flaccid paralysis are collectively referred to as neuroinvasive disease; others are considered non-neuroinvasive disease. Nonhuman arboviral surveillance is voluntary and performed variably across different jurisdictions. Data typically reported to ArboNET for nonhuman arboviral infections include animal species, state and county, and date of symptom onset or specimen collection. Reporting of total numbers of mosquitoes or birds tested is encouraged, but reporting of these data is often incomplete.

The assessment tool was designed to collect information regarding types of surveillance conducted in each jurisdiction, user satisfaction with ArboNET's performance, and how the data were used. In addition, ques-

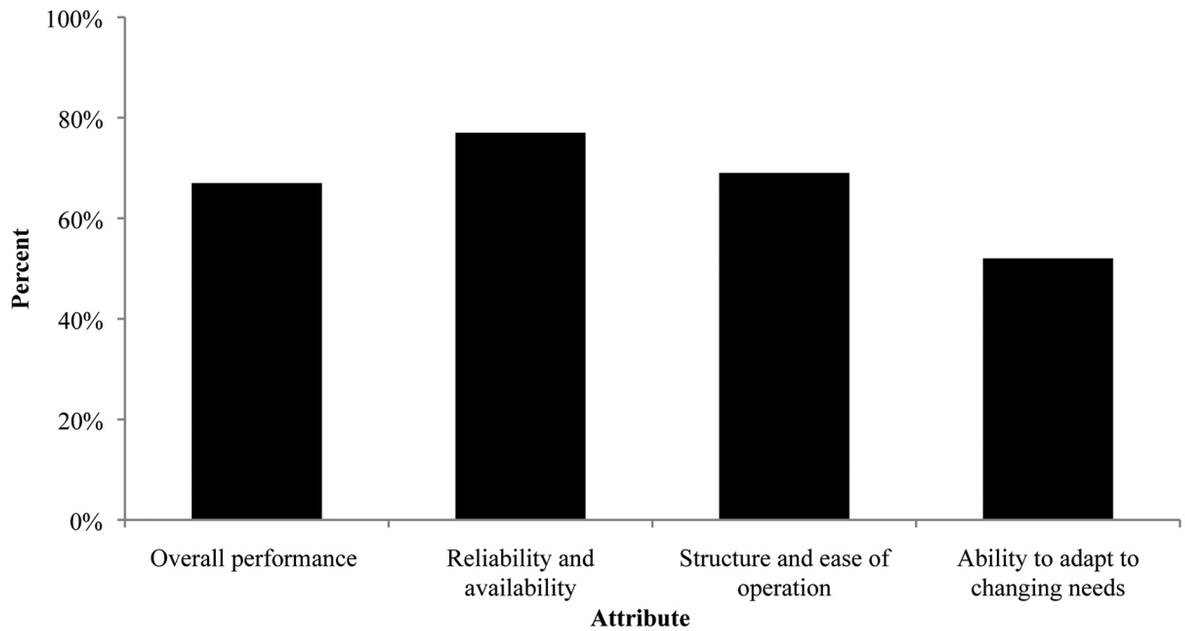
tions were asked about proposed changes to ArboNET and national arboviral surveillance and jurisdictions' ability and willingness to provide additional data. In the spring of 2009, the assessment was distributed by the Council of State and Territorial Epidemiologists (CSTE) to state and territorial epidemiologists in all 53 reporting jurisdictions via SurveyMonkey™, an online administration tool.[11] State epidemiologists could either complete the assessment themselves or forward it to another appropriate respondent within the jurisdiction. Participants were asked to provide responses representing the official opinions and interests of their jurisdictions, not merely personal opinions. We calculated the proportion of jurisdictions providing each response. For a subset of questions, these proportions were calculated after categorizing jurisdictions by WNV neuroinvasive disease incidence. Jurisdictions were categorized according to incidence of WNV neuroinvasive disease as high incidence (≥0.50 incidents per 100,000 population, $n$=18), medium incidence (0.10–0.49 incidents per 100,000 population, $n$=19), or low incidence (<0.10 incidents per 100,000 population, $n$=16) using the mean annual incidence of WNV neuroinvasive disease reported from 1999 through 2008.[3]

## RESULTS

Of the 53 assessments distributed, 48 (91%) were completed. Of the 46 respondents who provided their titles, 28 (61%) were vector-borne disease surveillance coordinators, seven (15%) were state epidemiologists, six (13%) were state public health veterinarians, and five (11%) were staff epidemiologists. Most respondents (67%) were satisfied with the overall performance of the system as compared with other national disease surveillance systems (Figure 1). Respondents were generally satisfied with the system's reliability/availability (77%) and structure/ease of operation (69%). Approximately half of users were satisfied with the ability of the system to accommodate and adapt to changes in events under surveillance, case definitions, and technology.

National arboviral surveillance data are currently used by state and local health departments in a variety of ways, particularly to provide information to state and local stakeholders and monitor national and regional epidemiology. Table 1 lists the reported current uses of ArboNET data by the 48 jurisdictions. Among the national reports routinely generated, users found the weekly USGS maps (92%) and the weekly CDC tables

**Figure 1. Percentage of U.S. state and territorial health departments satisfied with the performance of the ArboNET[a] surveillance system, as reported in a 2009 assessment ($n$=48)**




[a]ArboNET is a passive electronic surveillance system managed by the Centers for Disease Control and Prevention. Arboviral surveillance data are reported to ArboNET by 50 state and three local or territorial health departments (New York City, the District of Columbia, and Puerto Rico).

**Table 1. Current uses of ArboNET[a] surveillance data by U.S. state and territorial health departments, as reported in a 2009 assessment**

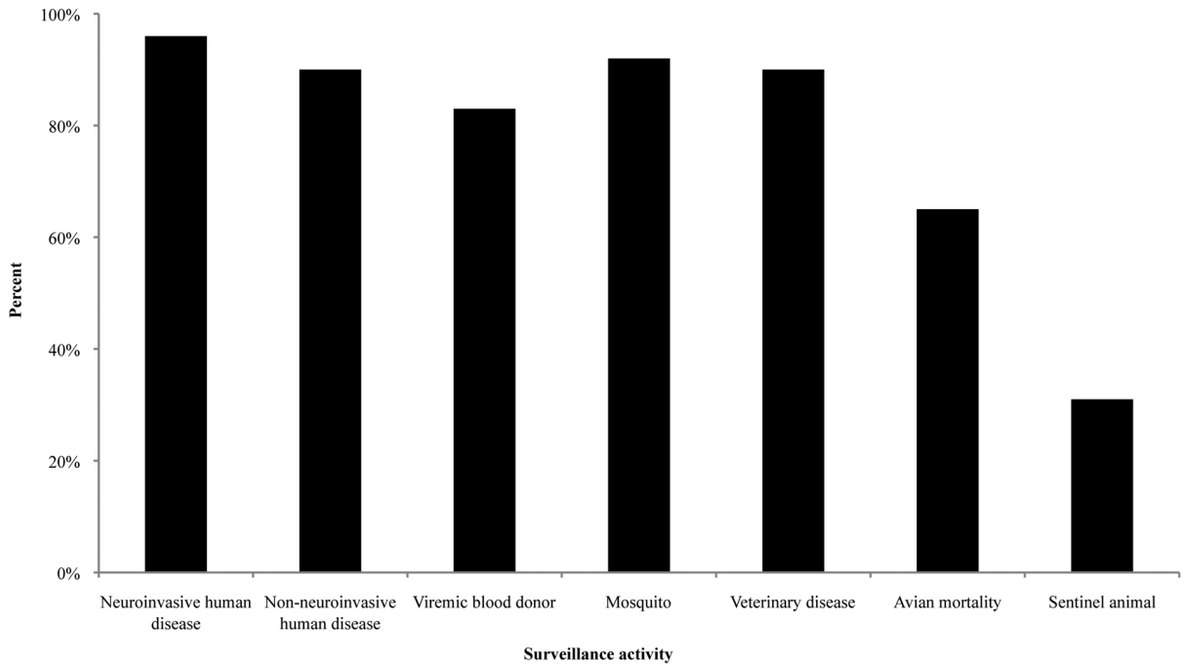
| | *Jurisdictions (n=48)* |
|---|---|
| *Current uses of ArboNET data* | N *(percent)* |
| Provide information to state and local stakeholders | 43 (90) |
| Monitor national and regional epidemiology during the season | 42 (88) |
| Prepare presentations and publications | 40 (83) |
| Make public health decisions | 36 (75) |
| Summarize national and regional epidemiology at end of season | 35 (73) |
| Cross-check official state surveillance numbers | 29 (60) |
| Determine allocation of funds and resources | 22 (46) |
| Conduct research | 15 (31) |
| Do not use ArboNET data | 1 (2) |

[a]ArboNET is a passive electronic surveillance system managed by the Centers for Disease Control and Prevention. Arboviral surveillance data are reported to ArboNET by 50 U.S. state and three local or territorial health departments (New York City, the District of Columbia, and Puerto Rico).

and maps (88%), both of which are available on the Internet, to be most useful. However, there were a number of suggestions for improvements to these websites. For example, many respondents (85%) reported that it would be useful to be able to view multiple data types simultaneously on the USGS maps. Some jurisdictions suggested including on maps an indication of timing of reports to better track the progression of seasonal activity and/or outbreaks. Additionally, an online interactive data-querying tool was suggested, particularly to allow for easier access to historical data (data not shown).

Most respondents reported that surveillance for human arboviral neuroinvasive disease cases (96%), non-neuroinvasive disease cases (90%), PVDs (83%), infections in mosquitoes (92%), and veterinary diseases (90%) was conducted in their jurisdictions in 2008 (Figure 2). All jurisdictions with a high or medium incidence of neuroinvasive disease also conducted

**Figure 2. Arboviral disease surveillance activities performed by U.S. state and territorial health departments in 2008, as reported in a 2009 assessment (*n*=48)**



surveillance for non-neuroinvasive disease compared with 77% of low-incidence jurisdictions. PVD surveillance was conducted in 100% of high-incidence, 81% of medium-incidence, and 77% of low-incidence jurisdictions. Mosquito surveillance was conducted in 100% of high-incidence, 88% of medium-incidence, and 85% of low-incidence jurisdictions. Surveillance for arboviral infections in dead birds and sentinel animals was conducted less frequently (data not shown).

Although 83% of the jurisdictions reported the number of mosquito pools that tested positive for arbovirus infections (i.e., numerator data), only 58% reported the total numbers of mosquitoes trapped and tested (i.e., denominator data). Similarly, more jurisdictions reported the number of dead birds found in the community that tested positive (63%) than the total numbers of birds tested (42%). Commonly stated obstacles to reporting the numbers of birds and mosquitoes tested were the time and resources required to collect and report these data. Nearly all (92%) respondents said that they were willing to provide an annual list of surveillance activities conducted within their jurisdictions, but only 18 (38%) said that they would be able to enumerate these activities at the county level (data not shown).

Most respondents stated that human, mosquito, and veterinary arboviral surveillance data are useful (Table 2). High-incidence jurisdictions were less likely to report that veterinary disease (67%), avian mortality (53%), and sentinel animal (27%) surveillance data were useful than medium- and low-incidence jurisdictions (90%, 79%, and 62%, for veterinary disease, avian mortality, and sentinel animal surveillance data, respectively) (data not shown). Although there was not strong agreement on the usefulness of avian mortality (65%) and sentinel animal (48%) surveillance (Table 2), only 15% of respondents were in favor of eliminating these data categories from ArboNET (data not shown). No low-incidence states supported the elimination of any nonhuman surveillance data categories. As shown in Table 3, few respondents reported that funding cuts had caused them to decrease or eliminate surveillance for human disease cases or PVDs. However, many respondents said that funding cuts had caused them to decrease or eliminate nonhuman surveillance efforts, particularly for mosquitoes (63%) and dead birds (60%).

Many comments expressed dissatisfaction with data transmission mechanisms, particularly the system's inability to accept National Electronic Disease Surveillance System (NEDSS)-compliant messages. This incompatibility has resulted in double data entry for many jurisdictions. Most respondents (60%) said that their jurisdictions had electronic surveillance systems that were capable of sending Health Level Seven International messages to NEDSS. Twenty jurisdictions (42%) reported that they would find it useful to receive additional training on ArboNET data-entry and transmission mechanisms. In addition, respondents reported that it would be useful to be able to access historical data (94%) and import tabular data to the system (77%) (data not shown).

**Table 2. U.S. state and territorial health departments that consider human and nonhuman ArboNET[a] surveillance data to be useful, by surveillance category, as reported in a 2009 assessment**

| | *Jurisdictions (n=48)* |
|---|---|
| *Surveillance activities* | N *(percent)* |
| Human surveillance | |
| Neuroinvasive disease | 39 (81) |
| Non-neuroinvasive disease | 38 (79) |
| Presumptively viremic blood donors | 38 (79) |
| Nonhuman surveillance | |
| Mosquitoes | 41 (85) |
| Veterinary disease | 36 (75) |
| Avian mortality | 31 (65) |
| Sentinel animals | 23 (48) |

[a]ArboNET is a passive electronic surveillance system managed by the Centers for Disease Control and Prevention. Arboviral surveillance data are reported to ArboNET by 50 state and three local or territorial health departments (New York City, the District of Columbia, and Puerto Rico).

**Table 3. U.S. state and territorial health departments that have decreased or eliminated arboviral surveillance activities as a result of decreased federal funding, as reported in a 2009 assessment**

| | *Jurisdictions (n=48)* |
|---|---|
| *Surveillance activities* | N *(percent)* |
| Human surveillance | |
| Investigation of human neuroinvasive disease cases | 3 (6) |
| Investigation of human non-neuroinvasive disease cases | 5 (10) |
| Investigation of presumptively viremic blood donors | 2 (4) |
| Nonhuman surveillance | |
| Surveillance for veterinary disease cases | 17 (35) |
| Surveillance for mosquitoes | 30 (63) |
| Surveillance for avian mortality | 29 (60) |
| Maintenance and surveillance of sentinel animals | 18 (38) |

When jurisdictions were queried about several proposed changes to ArboNET and national arboviral surveillance, respondents were generally supportive (71%) of a review and possible revision of the national arboviral surveillance case definition. There was also support (65%) for the identification and funding of arboviral surveillance sentinel sites. There was less support (54%) for expanding ArboNET to include other vector-borne infectious diseases; cited reasons for opposing the expansion included lack of necessary funding and excessive time required to enter reports because of NEDSS incompatibility (data not shown).

Jurisdictions were queried on their ability and willingness to provide additional clinical (e.g., signs and symptoms) and laboratory (e.g., specimen type, specimen collection date, and type of test performed) data for human arboviral disease cases. Most respondents (88%) currently collect clinical data and would be willing to report them to ArboNET (73%) (Table 4). Most respondents also currently collect laboratory data (90%), specifically arboviral diagnostic testing results, and would be willing to report them (63%). There was a lack of agreement on whether it would be useful to report additional clinical (58%) or laboratory (52%) data to ArboNET. Cited obstacles to reporting these additional data were primarily related to the time and resources required to collect and report this information. Sixty-seven percent of respondents reported that they currently report travel-associated or imported human arboviral disease cases; a larger proportion (79%) said that they were willing to report these data. Most respondents (65%) said that reporting imported cases would be useful (Table 4). Stated obstacles to reporting imported cases included difficulty in confirming diagnoses, lack of support for reporting diseases that are not designated as nationally notifiable, and lack of standardized surveillance case definitions (data not shown).

## DISCUSSION

Given the changing trends in arboviral epidemiology and the increasingly limited availability of funding to support arboviral surveillance, continued evaluation and modification of ArboNET is essential to ensure that surveillance is as efficient and useful as possible. The assessment described in this article was conducted as part of a broad evaluation of ArboNET performed by a working group representing primary stakeholders in arboviral surveillance. The objectives of the overall evaluation were to evaluate the quality and utility of ArboNET data, identify and implement changes to better serve ArboNET users, and develop a five-year plan for national arboviral surveillance. The findings of the user assessment were considered in combination with the findings of other evaluation components to identify areas of greatest concern and develop recommendations for improvement.

In general, state and local health departments found ArboNET data to be useful and were satisfied with the performance of ArboNET relative to other national disease surveillance systems. Surveillance for human arboviral disease cases is conducted in most jurisdictions. Although slightly fewer jurisdictions conducted surveillance for viremic blood donors, PVD surveillance data were reported to be as useful as human disease surveillance data. Surveillance for nonhuman infections is more variable and appears to depend on funding and incidence of disease. If funding to support arboviral surveillance continues to decrease, it seems likely that fewer jurisdictions will be able to maintain robust nonhuman surveillance programs. This change

**Table 4. U.S. state and territorial health departments that already collect additional human arboviral disease surveillance data, would be willing to report additional data, and think it would be useful to have additional data reported to ArboNET[a] as reported in a 2009 assessment (*n*=48)**

| *Human disease data* | *Collect data*[b] N *(percent)* | *Willing to report data*[c] N *(percent)* | *Data would be useful*[d] N *(percent)* |
|---|---|---|---|
| Human clinical data | 42 (88) | 35 (73) | 28 (58) |
| Human laboratory data | 43 (90) | 30 (63) | 25 (52) |
| Imported human disease cases[e] | 32 (67) | 38 (79) | 31 (65) |

[a]ArboNET is a passive electronic surveillance system managed by the Centers for Disease Control and Prevention. Arboviral surveillance data are reported to ArboNET by 50 state and three local or territorial health departments (New York City, the District of Columbia, and Puerto Rico).

[b]Jurisdictions that already collect or receive these data through routine surveillance

[c]Jurisdictions that are willing to report, or collect and report if necessary, additional data to ArboNET

[d]Jurisdictions that think it would be useful to have these additional data available in ArboNET

[e]Includes travel-associated cases of yellow fever, Japanese encephalitis, dengue, and tick-borne encephalitis

will decrease our ability to detect virus activity with adequate time to implement public health control measures to prevent human disease epidemics or outbreaks. Mosquito surveillance data were reported to be the most useful when compared with other surveillance categories, perhaps because arboviral infections in mosquitoes are an indicator of immediate human risk and can be reported without the delays associated with investigating human infections. While there was disagreement on the utility of avian mortality and sentinel animal surveillance, there was little support for eliminating these or any other data categories from ArboNET, particularly among lower-incidence states, which were more likely to find nonhuman surveillance data useful. Jurisdictions seemed reluctant to support the elimination of data categories that might be useful to others, especially as reporting of nonhuman data is voluntary.

The variability in nonhuman surveillance practices is one of the major limitations of ArboNET data. Establishing a mechanism to record the relative completeness and intensity of surveillance activities of each jurisdiction at the beginning of each season would assist with data interpretation. Almost all jurisdictions reported that they would be willing to do so to some extent.

Many specific complaints were related to problems with data transmission and manipulation, particularly the historic lack of NEDSS compatibility. ArboNET has recently been updated to accept NEDSS-compliant messages to facilitate integration with other state and national electronic surveillance systems. This new mechanism of data transmission was piloted in one state in 2009 and was made available to all states prior to the start of the 2010 arboviral transmission season. Since this survey was completed, two ArboNET user-training sessions have been held. Site visits may be planned in the future in response to other identified problems and to ensure that users are making the most efficient use of ArboNET.

Arboviral disease summary data and maps continue to be available on CDC, USGS, and Public Health Agency of Canada websites, which are updated weekly during the arboviral transmission season. More detailed data are available by request; ArboNET data-release guidelines have been revised to be consistent with those recommended by CSTE. A newly revised weekly domestic arboviral disease report, which now includes data reported for La Crosse virus, eastern equine encephalitis virus, Powassan virus, St. Louis encephalitis virus, and WNV, is circulated to state and local health department partners by e-mail and is posted to Epi-X. Other options to improve ArboNET user ability to access, export, manipulate, and analyze data, including the ability to query data, retrieve data in tabular format, superimpose layers of geospatial data, and access historical data, are being investigated.

There was general support for a review and possible revision of the national case definition for human arboviral disease. CSTE and CDC reviewed and revised the case definition, and the revised definition was adopted at the 2010 CSTE Annual Conference. The addition of laboratory variables to ArboNET, including type of laboratory test, is under consideration. Reporting additional human clinical and laboratory data to ArboNET would allow for some confirmation of case classification and case status at the national level. Although most jurisdictions are willing and able to report additional human clinical and laboratory data to ArboNET, time and resource constraints must be carefully considered before additional data fields are incorporated into the system.

### Limitations

The findings of this study were subject to at least two limitations. For one, the methods used by respondents to rate ArboNET's utility and performance were subjective and likely varied by jurisdiction. Participants were asked to provide responses representing the official opinions and interests of their jurisdictions, but it is possible that some respondents provided personal opinions. Secondly, although 91% of jurisdictions completed the assessment, the results might have differed if all jurisdictions had completed the assessment.

## CONCLUSIONS

This article presents findings from the first assessment of the perceived utility of and user satisfaction with the ArboNET surveillance system. Most users were satisfied with the performance of ArboNET. Users disagreed about the usefulness of some surveillance data categories, but most did not support the elimination of any categories from ArboNET. Although many jurisdictions are willing to report additional clinical and laboratory data, time and resource constraints and data utility need to be considered before supplemental fields are added to the system. As a result of this assessment, CDC and partner organizations have made ArboNET NEDSS-compatible, revised national case definitions for arboviral disease, and revised routine ArboNET reports. Other proposed changes are being considered and may be implemented during the coming years. Continued evaluation of ArboNET will help ensure that it continues to be a useful tool for national arboviral disease surveillance.

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# A Comparison of Two Surveillance Strategies for Selected Birth Defects in Florida

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## ABSTRACT

**Objective.** We linked data from two independent birth defects surveillance systems with different case-finding methods in an overlapping geographic area to assess Florida's suveillance of birth defects (e.g., neural tube defects, orofacial clefts, gastroschisis/omphalocele, and chromosomal defects), focusing on sensitivity and completeness of ascertainment measures.

**Methods.** Live-born infants identified from each system born during 2003–2006 in a nine-county catchment area with specific birth defects were linked to birth certificates. Using the enhanced surveillance system as a gold standard, we calculated the sensitivity of the Florida Birth Defects Registry (FBDR) for identifying infants. Next, we used capture-recapture models to estimate the completeness of case ascertainment and the prevalence of each birth defect in the catchment area. We used multivariable logistic regression models with backward elimination to estimate adjusted odds ratios and 95% confidence intervals for factors significantly associated with the FBDR's failure to capture infants ultimately identified by enhanced surveillance.

**Results.** The FBDR's sensitivity was 89.3%, and the overall completeness of ascertainment was estimated as 86.6%. Defect-specific sensitivity and completeness of ascertainment varied significantly by defect. The combined defect-specific sensitivity for all malformations under study was 86.6%; completeness of ascertainment ranged from 45.6% for anencephaly to 88.6% for Down syndrome, 87.9% for spina bifida without anencephaly, and 87.0% for orofacial clefts.

**Conclusions.** For the defects under study, the FBDR captured nearly nine of every 10 infants born with selected birth defects. However, the FBDR's ability to identify specific defects was both more limited and defect dependent with widely varying defect-specific sensitivities.

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Public health surveillance programs use a variety of approaches to identify cases that lie on a continuum ranging from "passive" to "active."[1] Active birth defect case ascertainment is a labor-intensive process involving staff finding cases through direct review of primary data sources, which include medical records, hospital/nursery logs, autopsy reports, and ambulatory care settings. Completeness of ascertainment is very high, and each birth defect diagnosis is confirmed. Passive ascertainment involves physician or facility filing of case reports or identification of birth defect cases using secondary data sources, such as inpatient and outpatient discharges and vital records, and relying primarily on International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) diagnostic codes, which may or may not be confirmed. Most states, depending on the number of infants diagnosed with a birth defect, budget, staff, and objectives, structure their activities around one approach on the active-passive continuum.[2] While active case finding is generally regarded as the most scientific and rigorous method of determining birth defects, this approach requires considerable personnel and travel resources.

The purpose of this study was to evaluate the capacity of the Florida Birth Defects Registry (FBDR) to identify infants with birth defects by comparing and contrasting the two birth defects surveillance approaches. In doing so, we sought to (*1*) determine the sensitivity of the FBDR for selected defects, (*2*) estimate the completeness of ascertainment of the FBDR, and (*3*) identify infant and maternal characteristics associated with the FBDR's failure to identify infants captured by the enhanced surveillance system.

## METHODS

This study involved linking two surveillance systems to examine more than 2,000 infants born from January 1, 2003, to December 31, 2006, identified with specific defects in the first year of life (subsequently referred to as "cases") to compare and contrast two birth defects surveillance approaches.

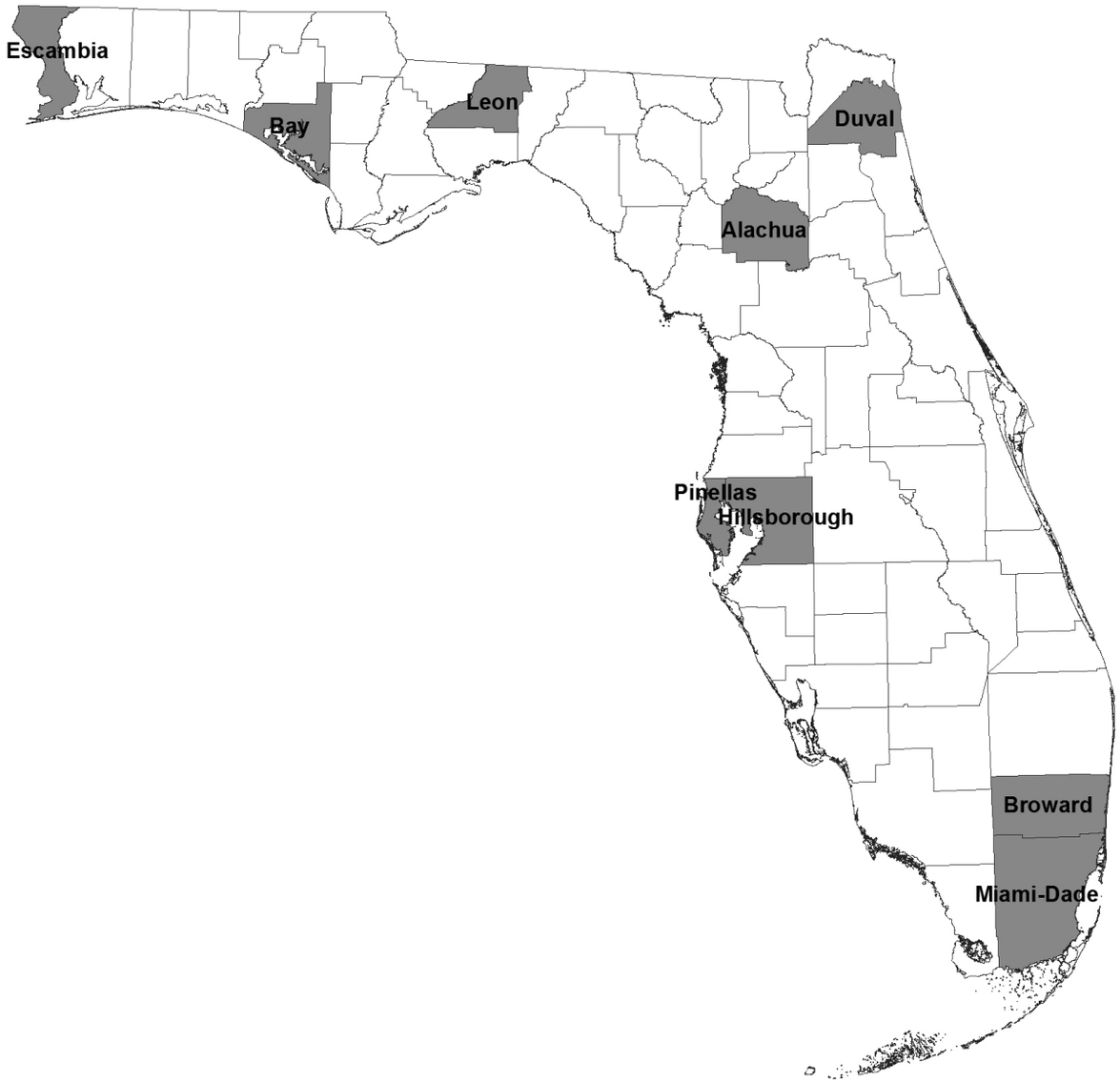
### Passive surveillance system: the Florida Birth Defects Registry

The FBDR was established in 1999 as a passive, statewide, population-based birth defects surveillance system to protect and promote the health of people in Florida by detecting, investigating, and preventing birth defects. The FBDR's inclusion criteria include the following: (*1*) the mother is a Florida resident; (*2*) the infant is live born and diagnosed in the first year of life with one or more structural, genetic, or other specified birth outcomes that can adversely affect an infant's health and development (most fall in the ICD-9-CM 740–759.9 code range); and (*3*) the date of delivery is on or after January 1, 1998. The FBDR's passive case-ascertainment methodology involves linking multiple secondary "source" datasets, including vital birth records, the Agency for Health Care Administration (AHCA) hospital inpatient and ambulatory discharge databases, Regional Perinatal Intensive Care Centers (RPICC) data, Children's Medical Services (CMS) case-management records, and CMS Early Steps data. AHCA collects and reports on hospital inpatient, ambulatory, and emergency department discharge data from a variety of facilities, including, but not limited to, acute care hospitals, short-term psychiatric facilities, comprehensive rehabilitation facilities, long-term psychiatric facilities, ambulatory surgical centers, lithotripsy centers, and cardiac catheterization laboratories. The 11 RPICC hospitals provide obstetrical services to women with a high-risk pregnancy and care for newborns with special health needs. The CMS Early Steps program offers services to infants and young children with significant delays or conditions that may result in a developmental delay (e.g., certain birth defects). The FBDR has published data on the 1998–2007 birth cohorts.

### Enhanced surveillance system: the Centers for Disease Control and Prevention (CDC) Cooperative Agreement Project

In December 2003, the Florida Department of Health (FDOH) entered into a contract with the Birth Defects Surveillance Program (BDSP) at the University of South Florida to develop and operate an enhanced surveillance project with funding from CDC. BDSP staff reviewed hospital medical records for suspected cases meeting specific eligibility criteria to verify each birth defect diagnosis and collect detailed data on confirmed cases. Confirmed cases also met the following eligibility criteria: (*1*) birth in Florida or maternal Florida residency during pregnancy; (*2*) receipt of care, or birth, in one of the catchment counties (Figure 1), which consisted of major metropolitan areas throughout the state that encompassed approximately 51% of the state's resident live births; (*3*) diagnosis of select birth defect(s) either during the prenatal period or postnatal period up to one year of age; and (*4*) ICD-9-CM discharge diagnosis codes indicative of central nervous system defects (740.0–742.9), absence of external ear (744.01), microtia (744.23), orofacial clefts (749.0–749.2), gastroschisis/omphalocele (756.79), chromosomal abnormalities (758.0–758.2), or maternal prenatal codes of fetal abnormalities affecting the

**Figure 1. Enhanced surveillance system nine-county catchment area, Florida, 2003–2006**




management of the mother (655.0–655.6, 655.8–655.9) and intrauterine death (656.4). The enhanced surveillance project included all confirmed cases born from January 1, 2003, to December 31, 2006.

**Linking the surveillance systems**

During database construction, all FBDR case records are linked to birth certificate data. Using a stepwise deterministic linkage strategy, supplemented with manual record matching, we attempted to link all live-born cases identified by the enhanced surveillance system to the same birth certificate records used in the FBDR's construction. Of 2,206 live-born cases in the enhanced surveillance project that were eligible for this comparative study, we were able to link 2,173 (98.5%) to a birth record. The 33 unlinked cases excluded from this study consisted of records lacking a significant amount of identifiable information (e.g., infant's and mother's names, dates of birth, or Social Security numbers) required to establish a link to the birth record. To establish a common dataset for all analyses, we further restricted the dataset to 1,734 cases born in the enhanced surveillance system's nine-county catchment area.

The eligibility criteria for this study incorporated overlapping inclusion criteria from each surveillance

system. With the exception of extending case ascertainment to stillbirths/fetal deaths in addition to live births, the case definition for the enhanced surveillance system was encompassed by the FBDR's case definition; thus, every live-born case identified by the enhanced surveillance system would also meet the eligibility criteria to be a case in the FBDR. The birth defects selected for this study included anencephaly; spina bifida without anencephaly; encephalocele; orofacial clefts; gastroschisis; omphalocele; and trisomies 13 (Patau syndrome), 18 (Edwards syndrome), and 21 (Down syndrome) (Figure 2).

**Statistical analyses**

All cases identified by the enhanced system would theoretically be captured by the FBDR if the FBDR's case ascertainment were complete. The enhanced surveillance system with case confirmation served as the gold standard for estimating the FBDR's sensitivity for identifying infants across all conditions studied and for specific birth defects. The FBDR's overall sensitivity represents the proportion of cases identified by enhanced surveillance that were also captured by the FBDR, regardless of the defects identified by the FBDR. In contrast, the FBDR's sensitivity for a specific defect represented the proportion of cases identified by enhanced surveillance that were also identified by the FBDR with the same defect. Sensitivity, using both definitions, is presented overall and by defect among all 1,734 cases ascertained during the enhanced surveillance project. For these analyses, infants were unduplicated at the level of the defect; however, an infant with multiple defects considered in this study may have been included in more than one defect-specific analysis.

In addition to sensitivity, we estimated the completeness of the FBDR's ascertainment of selected defects among infants born in the nine-county overlap between the catchment areas of the FBDR and the enhanced system using a simple two-source capture-recapture method.[3] Capture-recapture methods have been used increasingly in epidemiologic studies, primarily to evaluate the completeness of registration for cancer registries.[3–8] This approach uses overlapping information from two independent registries (i.e., the probability of detecting a case in one registry is the same regardless of whether or not the case is detected in the other registry) to estimate the extent of incomplete ascertainment. Because both birth defect systems have been linked, we can provide the number of cases captured by both sources. The total number of cases and the number of cases missed by both registries were estimated using a two-source capture-recapture model. The estimated completeness of ascertainment for the FBDR was then calculated by dividing the number of cases captured by the FBDR by the total number of cases estimated by the model. The completeness of ascertainment supplements sensitivity measures by accounting for the imperfect completeness of ascertaining the enhanced system. It also permitted the calculation of revised estimates of each defect's prevalence in the catchment area covered by both the FBDR and enhanced surveillance, for direct comparison with an FBDR-only system and national prevalence estimates.

We also conducted an analysis to identify characteristics associated with the FBDR's failure to capture infants with birth defects. Demographic and reproductive health data were obtained from the linked birth certificate files. We determined maternal race/ethnicity based on maternal self-report and first grouped women by ethnicity (Hispanic or non-Hispanic), with the non-Hispanic group further subdivided by race (non-Hispanic white, non-Hispanic black, or other).

**Figure 2. Birth defects included in the comparison of surveillance systems and their respective diagnostic codes: Florida, 2003–2006**

| *Birth defect type* | *Passive surveillance ICD-9-CM code(s)* | *Enhanced surveillance modified BPA code(s)* |
|---|---|---|
| Anencephaly | 740.0–740.1 | 740.00[a]–740.10[a] |
| Spina bifida without anencephaly | 741[a] without 740.0–740.1 | 741[a] without 740.00[a]–740.10[a] |
| Encephalocele | 742.0 | 742.00[a]–742.09[a] |
| Orofacial cleft[b] | 749[a] | 749[a] |
| Gastroschisis/omphalocele | 756.79 | 756.700, 756.710 |
| Trisomy 13 (Patau syndrome) | 758.1[a] | 758.10[a]–758.19[a] |
| Trisomy 18 (Edwards syndrome) | 758.2[a] | 758.20[a]–758.29[a] |
| Trisomy 21 (Down syndrome) | 758.0[a] | 758.00[a]–758.09[a] |

[a]Any valid digits following the given prefix were included in this category.

[b]Includes cleft lip and cleft palate

ICD-9-CM = International Classification of Diseases, Ninth Revision, Clinical Modification

BPA = British Pediatric Association

**Table 1. Overall and defect-specific sensitivity of the FBDR for selected birth defects: Florida, 2003–2006**

| *Birth defect* | *Total ESS cases* N | *ESS cases in FBDR*[a] N | *Sensitivity of FBDR Percent* | *ESS cases in FBDR for specified defect* N | *Defect-specific sensitivity of FBDR Percent* |
|---|---|---|---|---|---|
| Anencephaly | 44 | 22 | 50.0 | 20 | 45.5 |
| Spina bifida without anencephaly | 117 | 106 | 90.6 | 103 | 88.0 |
| Encephalocele | 40 | 32 | 80.0 | 29 | 72.5 |
| Orofacial cleft[b] | 607 | 554 | 91.3 | 528 | 87.0 |
| Gastroschisis/omphalocele | 352 | 310 | 88.1 | 298 | 84.7 |
| Patau syndrome | 42 | 33 | 78.6 | 26 | 61.9 |
| Edwards syndrome | 65 | 52 | 80.0 | 49 | 75.4 |
| Down syndrome | 539 | 492 | 91.3 | 478 | 88.7 |
| Any included defect | 1,734 | 1,548 | 89.3 | 1,501 | 86.6 |

[a]Identified with any International Classification of Diseases, Ninth Revision, Clinical Modification diagnosis code included in the FBDR

[b]Includes cleft lip and cleft palate

FBDR = Florida Birth Defects Registry (passive surveillance system)

ESS = enhanced surveillance system

Maternal nativity was dichotomized as U.S.-born or foreign-born (i.e., born outside the 50 U.S. states). We categorized maternal age as <20 years, 20–34 years, or ≥35 years of age, and maternal education as <12 years, 12 years, or >12 years. We designated plurality as singleton or multiple. Gestational age was categorized as preterm (20–36 weeks gestation) or term (≥37 weeks gestation) based on the mother's date of last menstrual period (LMP). When the LMP was missing, we substituted the clinical estimate of gestation. We grouped birth weight as very low (<1,500 grams), low (1,500–2,499 grams), and normal (≥2,500 grams). Due to the collinear nature of gestational age and birth weight, we created a combination variable and used the six resultant combinations in analyses. Failure of an infant to be captured by the FBDR was defined as a live-born infant who was identified by the enhanced surveillance system as having one of the defects under study but who was not captured by the FBDR. Using this definition, an infant in the FBDR was considered captured regardless of the birth defects identified.

We calculated descriptive statistics for each of the aforementioned covariates as well as infant gender, and stratified them by whether the enhanced surveillance case infant was captured by the FBDR. We used a multivariable unconditional logistic regression model with backward elimination to estimate the adjusted odds ratios (AORs) and 95% confidence intervals (CIs) for factors significantly associated with the FBDR's failure to capture an infant identified by enhanced surveillance. All statistical tests were two-sided and declared significant at $p<0.05$. We performed statistical analyses using SAS® version 9.2.[9]

## RESULTS

The overall and defect-specific sensitivity of the FBDR for selected birth defects is provided in Table 1. Results of this methodologic comparison indicated an overall sensitivity of 89.3%, as 1,548 out of 1,734 infants identified as a case by the enhanced surveillance system were captured by the FBDR. With the exception of anencephaly, the FBDR performed well, identifying 79%–91% of infants identified by the enhanced surveillance system for each defect under study. The overall and defect-specific sensitivity was lower when the more restrictive definition of sensitivity was used, requiring the FBDR to identify the infant as having the same defect as did the enhanced surveillance system. The combined defect-specific sensitivity for all malformations under study was 86.6%, and ranged from 45.5% for anencephaly to 88.7% for Down syndrome.

The estimated overall completeness of ascertainment was 86.6% (95% CI 85.8, 87.3) (Table 2). For the capture-recapture analysis, we considered 2,107 infants born in the enhanced surveillance system's nine-county catchment area that were identified by either the FBDR ($n$=1,874) or the enhanced system ($n$=1,734) as having one of the selected defects of interest. Of these, 1,501 cases were identified by both the FBDR and the enhanced system. The capture-recapture model estimated a total of 2,165 cases with these selected defects, born in the catchment area, with an estimated 58 cases missed by both systems. Similar to findings on sensitivity, defect-specific completeness of ascertainment varied significantly by defect, ranging from 45.6% for anencephaly to more than 88.6% for Down syndrome, 87.9% for spina bifida without anencephaly, and 87.0% for orofacial clefts.

**Table 2. Completeness of ascertainment of the FBDR for selected birth defects: Florida, 2003–2006**

| Birth defect | Total cases from FBDR N | Total cases from ESS N | Overlap cases in both N | Estimated[a] uncaptured cases N | Estimated total cases N | Estimated completeness of ascertainment Percent (95% CI) |
|---|---|---|---|---|---|---|
| Anencephaly | 26 | 44 | 20 | 8 | 57 | 45.6 (39.8, 53.4) |
| Spina bifida without anencephaly | 152 | 117 | 103 | 7 | 173 | 87.9 (84.7, 91.3) |
| Encephalocele | 45 | 40 | 29 | 7 | 62 | 72.6 (65.4, 81.5) |
| Orofacial cleft[b] | 621 | 607 | 528 | 14 | 714 | 87.0 (86.0, 88.0) |
| Gastroschisis/omphalocele | 370 | 352 | 298 | 14 | 438 | 84.5 (82.9, 86.2) |
| Patau syndrome | 45 | 42 | 26 | 12 | 73 | 61.6 (53.8, 72.2) |
| Edwards syndrome | 71 | 65 | 49 | 8 | 95 | 74.7 (69.5, 80.8) |
| Down syndrome | 615 | 539 | 478 | 18 | 694 | 88.6 (87.4, 89.9) |
| Any included defect | 1,874 | 1,734 | 1,501 | 58 | 2,165 | 86.6 (85.8, 87.3) |

[a]Estimated using simple two-source capture-recapture modeling

[b]Includes cleft lip and cleft palate

FBDR = Florida Birth Defects Registry (passive surveillance system)

ESS = enhanced surveillance system

CI = confidence interval

Capture-recapture modeling permitted a revised estimation of each defect's prevalence in the catchment area covered by enhanced surveillance. We compared these revised estimates with existing estimates generated by the FBDR, as well as national estimates generated from 11 active surveillance programs around the country (Table 3).[10] Revised prevalence estimates predicted by capture-recapture modeling tended to be closer to national prevalence estimates than current FBDR estimates, particularly for neural tube defects (e.g., anencephaly and spina bifida without anencephaly) and orofacial clefts.

We were interested in determining whether any maternal or infant characteristics were associated with the FBDR's failure to capture a confirmed case. Table 4 describes these characteristics among the 1,734 cases identified by the enhanced surveillance system according to whether or not that infant was captured by the FBDR. Missed cases were more likely among multiple births; those born preterm and at very low birth weight; and those born of mothers who were Hispanic, born outside the U.S., and had <12 years of education. Multivariable logistic regression showed that following adjustment for other factors in the final

**Table 3. Prevalence of selected birth defects in Florida per 10,000 resident live births, 2003–2006**

| Birth defect | FBDR prevalence statewide | FBDR prevalence ESS catchment area | FBDR estimated[a] prevalence ESS catchment area | National estimates 1999–2001[b] Prevalence (95% CI) |
|---|---|---|---|---|
| Anencephaly | 0.4 | 0.6 | 1.2 | 2.1 (1.9, 2.2) |
| Spina bifida without anencephaly | 2.9 | 3.3 | 3.7 | 3.5 (3.3, 3.7) |
| Encephalocele | 0.9 | 1.0 | 1.3 | 0.8 (0.7, 0.9) |
| Orofacial cleft[c] | 15.6 | 13.4 | 15.4 | 17.0[d] (16.4, 17.6) |
| Patau syndrome | 0.7 | 1.0 | 1.6 | 1.3 (1.2, 1.4) |
| Edwards syndrome | 1.5 | 1.5 | 2.0 | 2.6 (2.5, 2.8) |
| Down syndrome | 13.3 | 13.2 | 14.9 | 13.6 (13.2, 13.9) |

[a]Estimated using simple two-source capture-recapture modeling

[b]Parker SE, Mai CT, Canfield MA, Richard R, Wang Y, Meyer RE, et al. Updated national birth prevalence estimates for selected birth defects in the United States, 2004–2006. Birth Defects Res A Clin Mol Teratol 2010;88:1008-16.

[c]Includes cleft lip and cleft palate

[d]Created by summing the individual estimates for cleft lip with and without cleft palate, and cleft palate alone

FBDR = Florida Birth Defects Registry (passive surveillance system)

ESS = enhanced surveillance system

CI = confidence interval

**Table 4. Distribution of maternal and infant characteristics among enhanced surveillance cases, by FBDR capture status: Florida, 2003–2006**

| | *Captured within the FBDR* | | |
|---|---|---|---|
| *Characteristic* | *Yes (n=1,548)* N *(percent)* | *No (n=186)* N *(percent)* | *Total (n=1,734)* N *(percent)* |
| Maternal age (in years) | | | |
| <20 | 205 (13.2) | 20 (10.8) | 225 (13.0) |
| 20–34 | 966 (62.4) | 119 (64.0) | 1,085 (62.6) |
| ≥35 | 377 (24.4) | 46 (24.7) | 423 (24.4) |
| Missing/unknown | 0 (0.0) | 1 (0.5) | 1 (0.1) |
| Maternal race/ethnicity | | | |
| Non-Hispanic white | 741 (47.9) | 67 (36.0) | 808 (46.6) |
| Non-Hispanic black | 314 (20.3) | 37 (19.9) | 351 (20.2) |
| Hispanic | 434 (28.0) | 72 (38.7) | 506 (29.2) |
| Non-Hispanic other | 50 (3.2) | 8 (4.3) | 58 (3.3) |
| Missing/unknown | 9 (0.6) | 2 (1.1) | 11 (0.6) |
| Maternal nativity | | | |
| U.S.-born | 1,056 (68.2) | 92 (49.5) | 1,148 (66.2) |
| Foreign-born | 488 (31.5) | 89 (47.8) | 577 (33.3) |
| Missing/unknown | 4 (0.3) | 5 (2.7) | 9 (0.5) |
| Maternal education | | | |
| <12 years | 365 (23.6) | 47 (25.3) | 412 (23.8) |
| 12 years | 507 (32.8) | 61 (32.8) | 568 (32.8) |
| >12 years | 649 (41.9) | 65 (34.9) | 714 (41.2) |
| Missing/unknown | 27 (1.7) | 13 (7.0) | 40 (2.3) |
| Infant gender | | | |
| Male | 815 (52.6) | 97 (52.2) | 912 (52.6) |
| Female | 732 (47.3) | 87 (46.8) | 819 (47.2) |
| Missing/unknown | 1 (0.1) | 2 (1.1) | 3 (0.2) |
| Plurality | | | |
| Singleton | 1,509 (97.5) | 166 (89.2) | 1,675 (96.6) |
| Multiple | 39 (2.5) | 20 (10.8) | 59 (3.4) |
| Gestational age/birth weight | | | |
| <37 weeks/<1,500 grams | 68 (4.4) | 44 (23.7) | 112 (6.5) |
| <37 weeks/1,500–2,499 grams | 192 (12.4) | 28 (15.1) | 220 (12.7) |
| <37 weeks/≥2,500 grams | 190 (12.3) | 17 (9.1) | 207 (11.9) |
| ≥37 weeks/<1,500 grams | 10 (0.6) | 2 (1.1) | 12 (0.7) |
| ≥37 weeks/1,500–2,499 grams | 175 (11.3) | 20 (10.8) | 195 (11.2) |
| ≥37 weeks/≥2,500 grams | 907 (58.6) | 67 (36.0) | 974 (56.2) |
| Missing/unknown | 6 (0.4) | 8 (4.3) | 14 (0.8) |

FBDR = Florida Birth Defects Registry (passive surveillance system)

model, maternal nativity, plurality, gestational age, and birth weight were significantly associated with the FBDR's failure to capture an infant with one of the selected defects under study (Table 5). Compared with term infants weighing ≥2,500 grams, those born preterm and <1,500 grams had more than eight times the odds of being missed by the FBDR (AOR=8.54, 95% CI 5.30, 13.78). Similarly, twins and higher order multiples had four times the odds of being missed than singletons (AOR=4.03, 95% CI 2.16, 7.50). Lastly, infants of foreign-born mothers had nearly three times the odds of being missed by the FBDR (AOR=2.56, 95% CI 1.83, 3.57).

## DISCUSSION

The results of this methodologic comparison indicate that for the defects under study, the FBDR captured nearly nine of every 10 infants born with selected birth defects. However, the FBDR's ability to identify specific defects was both more limited and defect dependent. We found that the FBDR had the best completeness of ascertainment for Down syndrome, spina bifida without anencephaly, and orofacial clefts. This finding supports our hypothesis that the ability of the FBDR to identify specific defects varies by characteristics of the defect,

including the medical care received by most infants with the defect.

Because the FBDR identifies infants with defects through diagnosis codes that may be present on any record in any of the source datasets, infants with a higher number of hospital admissions and a greater need for early intervention services offered by CMS would have more records eligible for data linkage and, thus, a higher probability of being captured by the FBDR. As an example, infants with a myelomenigocele may experience loss of bladder or bowel control, weakness, or partial or complete paralysis of the legs, which often requires continual medical care including surgeries and orthopedic or physical therapy. As a result, numerous inpatient and ambulatory discharge records, in addition to CMS service-related records, are created and are available for the FBDR's data linkage efforts. In contrast, infants with anencephaly are often stillborn or die within a few hours or days after birth. Typically, only a single hospital record is created for an anencephalic infant, and sometimes no records at all are created.[11] This paucity of records severely restricts the ability of the FBDR to capture such a case, leading to the FBDR's poor sensitivity and completeness of ascertainment for anencephaly and other rapidly fatal conditions.

In our study, 44 live-born cases of anencephaly were identified by the enhanced surveillance system, 22 of which were not captured by the FBDR with any included ICD-9-CM diagnosis code. Nine of those 22

**Table 5. Crude and adjusted ORs and 95% CIs for maternal and infant characteristics associated with the Florida Birth Defects Registry's failure to capture a case: Florida, 2003–2006**

| *Characteristic* | *OR (95% CI)* | *AOR[a] (95% CI)* |
|---|---|---|
| Maternal age (in years) | | |
| <20 | 0.79 (0.48, 1.30) | NS[b] |
| 20–34 | Ref. | NS[b] |
| ≥35 | 0.99 (0.69, 1.42) | NS[b] |
| Maternal race/ethnicity | | |
| Non-Hispanic white | Ref. | NS[b] |
| Non-Hispanic black | 1.30 (0.85, 1.99) | NS[b] |
| Hispanic | 1.84 (1.29, 2.61) | NS[b] |
| Non-Hispanic other | 1.77 (0.81, 3.89) | NS[b] |
| Maternal nativity | | |
| U.S.-born | Ref. | Ref. |
| Foreign-born | 2.09 (1.54, 2.86) | 2.56 (1.83, 3.57) |
| Maternal education | | |
| <12 years | 1.07 (0.72, 1.60) | NS[b] |
| 12 years | Ref. | NS[b] |
| >12 years | 0.83 (0.58, 1.20) | NS[b] |
| Infant gender | | |
| Male | Ref. | NS[b] |
| Female | 1.00 (0.74, 1.36) | NS[b] |
| Plurality | | |
| Singleton | Ref. | Ref. |
| Multiple | 4.66 (2.66, 8.18) | 4.03 (2.16, 7.50) |
| Gestational age/birth weight | | |
| <37 weeks/<1,500 grams | 8.76 (5.57, 13.78) | 8.54 (5.30, 13.78) |
| <37 weeks/1,500–2,499 grams | 1.97 (1.24, 3.15) | 1.80 (1.10, 2.93) |
| <37 weeks/≥2,500 grams | 1.21 (0.70, 2.11) | 1.20 (0.68, 2.10) |
| ≥37 weeks/<1,500 grams | 2.71 (0.58, 12.61) | 2.35 (0.44, 12.39) |
| ≥37 weeks/1,500–2,499 grams | 1.55 (0.92, 2.62) | 1.47 (0.86, 2.52) |
| ≥37 weeks/≥2,500 grams | Ref. | Ref. |

[a]Adjusted model includes maternal nativity, plurality, and gestational age/birth weight.

[b]Not significant in multivariable models

OR = odds ratio

CI = confidence interval

AOR = adjusted odds ratio

NS = not significant

Ref. = reference group

cases were identified on the birth certificate as having anencephaly. If the birth certificate were a valid case-ascertainment source for the FBDR, sensitivity of the FBDR for anencephaly reported in this study would have increased from 50% to 70%. This finding illustrates that passive surveillance programs should implement more extensive case-ascertainment strategies for anencephaly, including the addition of the anencephaly flag in the congenital anomalies section of the birth certificate as an additional source of cases, pending verification through chart review. Despite reports of poor sensitivity and specificity when considered in isolation,[12,13] the birth certificate could serve an important role in ascertainment as a supplemental dataset.

An equally important finding from the enhanced surveillance project was that medical record review of suspected cases (primarily identified by hospital ICD-9-CM codes) often resulted in the defect and case being ruled out as a false positive. This review step was only conducted in the enhanced surveillance method. Thus, the FBDR (whose case ascertainment is based solely on ICD-9-CM codes) may have a reduced positive predictive value; that is, an unacceptable proportion of FBDR-identified diagnoses may be determined to be false positives upon medical record review. As collecting data on cases ultimately excluded in the enhanced system was not part of the enhanced surveillance project's objectives, there were insufficient data to link these noncases to cases in the FBDR. Thus, a formal assessment of the FBDR's accuracy could not be made. However, this project demonstrated that a mechanism for confirming defect diagnoses would improve the FBDR's data quality substantially. In an era of limited funding and resources, the FDOH has continued to rely on the FBDR for reporting the frequency and prevalence of major birth defects. The incorporation of case verification procedures, particularly for specific defects, would increase the FBDR's positive predictive value and generate more accurate defect-specific prevalence estimates.

### Limitations

Our study was subject to several limitations. First, although we were able to link nearly all cases confirmed through enhanced surveillance to a live birth certificate record and, thus, to the FBDR, we were unable to link information on noncases. The original intent of the enhanced surveillance project was to improve ascertainment of the selected defects rather than to evaluate the FBDR, and collection of detailed information on noncases to the extent necessary to link to vital records was not included in the study design. This linkage would have provided insight into false-positive cases reported by the FBDR.

Second, the completeness of ascertainment estimated by capture-recapture modeling may have also been impacted by false-positive cases reported by the FBDR. False-positive FBDR cases would have led to an overestimation of the total number of cases and a resultant underestimation of completeness of ascertainment. However, we selected birth defects that are easily identified and diagnosed at birth (i.e., anencephaly, orofacial clefts, and gastroschisis), which should have minimized the impact of FBDR-generated false positives in this study.

A third potential limitation of this study relates to the primary assumption required for two-source capture-recapture modeling. We cannot ensure that there was no dependence between the two sources, as hospital-based information comprised a substantial portion of the ascertainment net cast by each surveillance system. However, different data streams were pursued from hospitals, with the FBDR using existing AHCA data, while the enhanced surveillance project involved specific requests to each hospital's information management system. Lastly, some gestational age-birth weight categories (e.g., <37 weeks/<1,500 grams, ≥37 weeks/<1,500 grams) had relatively small case counts, which resulted in wide CIs in multivariable models. These effect estimates should be interpreted with caution.

## CONCLUSIONS

Our findings offer insight into the capacity of a passive surveillance system that relies solely on data linkage and administrative diagnosis codes to identify infants with selected birth defects. The experiences gained from operating an enhanced surveillance system in a catchment area covering more than half of the state's resident live births allow Florida to develop strategies for improving its birth defect surveillance. To be better suited for use in epidemiologic or clinical studies, the FBDR must implement a more comprehensive case-ascertainment strategy that is comparable with the enhanced surveillance system.

The results of this study should be generalizable to other birth defects surveillance programs that use passive case-ascertainment strategies involving administrative health records databases. Our findings may help them to understand their completeness of ascertainment for selected defects and uncover characteristics of records that are difficult to link with other data sources. However, similar programs in other states may vary from the FBDR in duration of follow-up (e.g., some follow infants to age 2 years); whether prenatally diagnosed cases are included; and whether fetal deaths, spontaneous losses, or pregnancy terminations are included.

As few of these programs have conducted active case finding for comparative purposes, these results should be of interest to birth defects programs in a number of U.S. states.

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# Understanding Oral Health Promotion Needs and Opportunities of Tobacco Quitline Callers

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## ABSTRACT

**Objective.** Improving oral health and oral health care are important public health goals. Tobacco users and smokers are at particularly high risk for oral disease and warrant targeted intervention efforts. We assessed the need for and acceptability of targeting tobacco quitline callers for an oral health promotion intervention.

**Methods.** We surveyed 816 Washington State Quitline callers to assess their oral health, relevant self-care behaviors, and interest in oral health promotion intervention.

**Results.** Most respondents were female, cigarette smokers, of low socioeconomic status, with no dental insurance. Of the respondents, 79.3% ($n$=647) had some or all of their natural teeth (e.g., dentate); however, most of these respondents failed to meet recommendations for daily oral hygiene (brushing and flossing) (83.9%, $n$=543) and had no dental visits in the past year (52.6%, $n$=340). Similar findings were observed among respondents with no insurance. Many respondents were interested in learning more about how to improve their oral health (57.4%, $n$=468), willing to speak with a quitline coach about improving their oral health (48.2%, $n$=393), and open to receiving additional oral health information by mail (62.7%, $n$=512) or the Internet (50.0%, $n$=408). People who were receptive to learning how to improve their oral health were significantly more likely to be nonwhite, have a low income, have no dental insurance, and not have visited a dentist in the past year.

**Conclusion.** There is a need and an opportunity to target quitline callers for oral health promotion services, as those most in need of these services were open to receiving them.

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The Office of the Surgeon General and the Centers for Disease Control and Prevention recently called for greater partnerships between the public and private sector and the inclusion of health-care organizations, health insurers, and health professionals in efforts to promote oral health.[1,2] Oral diseases, including periodontal disease, dental caries, and oral and pharyngeal cancers, affect a large proportion of U.S. adults,[1,3–5] and they exact a large human and economic toll in the United States. Tobacco users are at particular risk for oral disease. More than 90% of cancers of the oral cavity and pharynx are caused by tobacco. Smoking is the second leading modifiable risk factor for periodontitis[1] and accounts for half of all periodontal disease.[6] Additionally, current smokers have a higher prevalence of untreated tooth decay than never smokers or former smokers,[5] and more smokers have unmet dental needs than nonsmokers.[5,7] In addition, smokers are more likely than nonsmokers to drink alcohol,[8–11] have poor nutrition,[12,13] and fail to seek routine health care,[14,15] and they are less likely than nonsmokers to visit the dentist.[16,17] These are all behaviors that increase oral disease risk. In short, tobacco users represent an important target group for oral health promotion efforts.

A novel way to reach tobacco users is to integrate oral health promotion efforts into existing state-sponsored tobacco quitline services. All 50 U.S. states offer free tobacco quitline programs to their state residents, reaching hundreds of thousands of tobacco users each year.[18] Key stakeholders from the nation's leading provider of tobacco quitline services (Alere Wellbeing, formerly known as Free & Clear, Inc.) and from the majority of states with whom they contract support the concept of integrating oral health into tobacco quitline services.[19] We evaluated the need for and feasibility of integrating oral health promotion with a tobacco quitline program based on survey data from a representative sample of callers to the Washington State Quitline (WAQL).

## METHODS

### Setting and participants

Callers to the WAQL from June to October 2010 were invited to participate in an oral health survey. Using an automated system built into the WAQL registration software, recruitment was randomly turned on and off each week to allow a steady flow of participants throughout the survey window. Within each open recruitment window, WAQL callers were systematically invited to participate at the time of their registration call. Callers were eligible for participation if they were at least 18 years of age, a current tobacco user, able to read and speak in English, calling the WAQL to enroll in services, and willing to provide consent for their contact information to be shared with Group Health Research Institute (GHRI) for the purpose of mailing the written survey. Invitees ($n$=1,591) represented 29% of all WAQL callers during the invitation window. Eighty-five percent of those invited ($n$=1,349) agreed to receive a mailed survey. Each of these callers was mailed a written survey and self-addressed, stamped return envelope. Invitees who did not return their initial survey within approximately two weeks were mailed a new survey and reminder letter. Four percent of surveys were returned due to invalid addresses, 35% were not returned, and 61% ($n$=816) were returned complete. Each respondent who returned a written survey received $10 as a thank you for participating.

### Assessment and data analysis

Assessment included standardized oral health, dental insurance, and smoking survey questions from the 2009 National Health and Nutrition Examination Survey (NHANES)[20] and 2008 Washington State Behavioral Risk Factor Surveillance System.[21] One NHANES item was modified slightly to read, "In the last seven days, how many days did you use dental floss or any device other than a toothbrush to clean between your teeth?" Participants were also asked about their interest in receiving oral health promotion services (yes/no), if they were available through the WAQL.

We used descriptive statistics to summarize survey results. We examined data for the entire sample, as well as among several key subgroups that would be likely targets of future interventions (i.e., dentate respondents [those with natural teeth], respondents with no dental insurance, and dentate respondents failing to meet American Dental Association [ADA] recommendations for basic oral self-care, defined as brushing at least twice a day and flossing daily). We used robust logistic regression to compare respondents' interest in oral health promotion services.

The sampling frame was designed to provide an adequate sample to generalize results to the broader WAQL population based on primary outcomes that were categorical (e.g., interest in oral health services [yes/no]), based on standard probability sampling metrics.[22,23] The obtained sample exceeded that required to generalize results to a population of one million or more with 95% confidence.[22] Annually, about 12,000 people call the WAQL.

## RESULTS

### Participant characteristics

Sample characteristics of respondents are shown in Table 1. Participants were predominantly non-Hispanic white, of low socioeconomic status, middle-aged (mean age = 43.1 years), female smokers. Demographic characteristics were similar to that of the entire population of callers during this time period based on aggregate WAQL data (80.3% white, 55.6% female, 54.0% with ≤high school education, mean age 49.1 years, and 96% cigarette smokers) (data not shown). The sample demographics were also consistent with prior published reports of WAQL callers and callers to some other state-supported quitlines.[24–26]

Most respondents had some or all of their natural teeth (79.3%, *n*=647) but did not have dental insurance (54.5%, *n*=445). A significant proportion of dentate respondents reported prior treatment for gum disease (21.6%, *n*=140), previous diagnosis of dental bone loss (20.4%, *n*=132), and an assumption of gum disease based on the presence of swollen, receding, sore, or infected gums, or loose teeth (42.8%, *n*=277) (Table 1).

### Oral health self-care

Self-reported oral health self-care behaviors among dentate individuals are presented in Table 2. Behaviors were not assessed among people with no natural teeth (i.e., edentulate respondents), which is consistent with NHANES. The majority of all dentate respondents (83.2%, *n*=538) and uninsured respondents (82.9%, *n*=295) failed to meet ADA-recommended guidelines for routine oral hygiene. In fact, only about two-thirds of respondents (*n*=376, 58.1%) reported brushing

**Table 1. Characteristics of callers to the Washington State Quitline who were eligible[a] to participate in an oral health survey: June–October 2010**

| | *All respondents (n=816)* | *Dentate respondents (n=647)* | *Respondents without dental insurance (n=445)* | *Respondents not meeting oral hygiene recommendations[b] (n=538)* |
|---|---|---|---|---|
| *Characteristics* | N *(percent)* | N *(percent)* | N *(percent)* | N *(percent)* |
| Age (in years) (mean [SD]) | 43.1 (13.5) | 41.3 (13.2) | 42.8 (13.8) | 40.5 (13.0) |
| Female | 503 (61.6) | 403 (62.3) | 262 (58.9) | 321 (59.7) |
| Non-Hispanic white | 643 (78.8) | 506 (78.2) | 356 (80.0) | 419 (77.9) |
| ≤High school education | 419 (51.3) | 311 (48.1) | 231 (51.9) | 265 (49.3) |
| Household income | | | | |
| <$20,000 | 500 (61.3) | 387 (59.8) | 275 (61.8) | 333 (61.9) |
| $20,000–$39,999 | 160 (19.6) | 128 (19.8) | 100 (22.5) | 107 (19.8) |
| ≥$40,000 | 84 (10.3) | 76 (11.7) | 31 (7.0) | 52 (9.7) |
| Current tobacco use | | | | |
| Cigarette smoker[c,d] | 725 (88.8) | 579 (89.5) | 406 (91.2) | 483 (89.8) |
| Pipe, cigar, or bidis[d] | 61 (7.5) | 47 (7.3) | 31 (7.0) | 42 (7.8) |
| Oral tobacco[d] | 49 (6.0) | 46 (7.3) | 31 (6.8) | 41 (7.6) |
| Oral health | | | | |
| Edentulate[e,f] | 163 (20.0) | NA | 83 (18.7) | NA |
| Ever treated for gum disease[e,g] | 140 (17.2) | 140 (21.6) | 72 (16.2) | 111 (20.6) |
| Think they have gum disease[e,g,h] | 277 (33.9) | 277 (42.8) | 154 (34.6) | 230 (42.8) |
| Diagnosed with dental bone loss[e,g,h] | 132 (16.2) | 132 (20.4) | 69 (15.5) | 100 (18.6) |

[a]To be eligible for the survey, callers had to be ≥18 years of age, a current tobacco user, able to read and speak in English, be calling the Washington State Quitline to enroll in services, and provide consent for their contact information to be shared with Group Health Research Institute for the written survey.

[b]Defined as dentate individuals who reported brushing less than twice daily and flossing fewer than seven days per week

[c]Defined as smoking 100 cigarettes in lifetime and smoking in past seven days

[d]Standardized items from the 2008 Washington State Behavioral Risk Factor Surveillance System

[e]Standardized items from the 2009 National Health and Nutrition Examination Survey

[f]Reported loss of all natural, permanent teeth

[g]Asked of dentate respondents only

[h]Based on current symptoms, including swollen gums, receding gums, sore or infected gums, or loose teeth

SD = standard deviation

NA = not applicable

**Table 2. Oral health behaviors among dentate respondents who were eligible[a] to participate in an oral health survey: Washington State Quitline, June–October 2010**

| | *All dentate respondents (n=647)* | *Dentate respondents without dental insurance (n=359)* | *Dentate respondents not meeting oral hygiene recommendations (n=538)* |
|---|---|---|---|
| *Oral health behaviors* | N *(percent)* | N *(percent)* | N *(percent)* |
| Times brush teeth daily (mean [SD])[b] | 1.8 (0.9) | 1.8 (0.9) | 1.6 (0.9) |
| Days floss per week (mean [SD])[b] | 2.9 (2.7) | 2.9 (2.8) | 2.1 (2.2) |
| Met ADA brushing recommendation[b,c] | 376 (58.1) | 217 (60.4) | 272 (50.6) |
| Met ADA flossing recommendation[b,d] | 131 (20.2) | 77 (21.4) | 27 (5.0) |
| Met ADA oral hygiene recommendations[b,e] | 104 (16.1) | 61 (17.0) | NA |
| Visited dentist or dental clinic in last 12 months[b] | 307 (47.4) | 133 (37.0) | 243 (45.2) |
| Self-reported health of teeth and gums as "good" or better[b,f] | 255 (39.4) | 137 (38.2) | 207 (38.5) |

[a]To be eligible for the survey, callers had to be ≥18 years of age, a current tobacco user, able to read and speak in English, be calling the Washington State Quitline to enroll in services, and provide consent for their contact information to be shared with Group Health Research Institute for the written survey.

[b]Standardized items from the 2009 National Health and Nutrition Examination Survey

[c]Having met ADA recommendations for brushing, defined as brushing at least twice per day

[d]Having met ADA recommendations for flossing, defined as flossing seven days per week

[e]Having met ADA recommendations for oral hygiene, defined as brushing at least twice per day and flossing seven days per week

[f]On a five-point Likert-scale, ranging from 1 = excellent to 5 = poor

SD = standard deviation

ADA = American Dental Association

NA = not applicable

their teeth twice daily. Additionally, most respondents (52.6%) had not received professional dental care in the past year.

**Interest in oral health promotion services**

Participants were asked about their interest in potential future oral health promotion services. Most individuals were interested in learning more about how to improve their oral health, willing to speak with a quitline counselor about improving their oral health, and open to receiving additional oral health information by mail or the Internet (Figure). Results were similar among people with and without their natural teeth, except that dentate respondents were more interested in learning more about how to improve their oral health. A similar pattern was observed comparing people with and without dental insurance (data not shown).

Compared with people who were not interested in learning more about ways to improve their oral health, those who were interested in learning more were more likely to be nonwhite (66.7% vs. 55.4% non-Hispanic white, odds ratio [OR] = 1.52, 95% confidence interval [CI] 1.01, 2.27; $p$=0.043), have a household income of <$20,000 per year (60.0% vs. 52.5% of people with an income of >$20,000/year, OR=1.57, 95% CI 1.13, 2.18; $p$=0.007), have no dental insurance (60.1% vs. 54.8% with insurance, OR=1.53, 95% CI 1.12, 2.09; $p$=0.008), and have not visited the dentist in the past year (63.9% vs. 59.7% of those who had visited the dentist, OR=1.49, 95% CI 1.05, 2.11; $p$=0.026) (data not shown). No other differences were observed based on demographics, tobacco use status, or whether or not people met oral hygiene recommendations.

## DISCUSSION

It has previously been suggested that oral health providers should intervene with smokers during dental visits.[6] However, because more than 40% of U.S. smokers report not regularly visiting the dentist,[5] we suggest that working with tobacco quitlines may also be an efficient way to reach tobacco users to promote oral health. To our knowledge, no attempts to integrate these services have ever been made. Yet, findings from this survey confirm that there is a need and an opportunity to target quitline callers based on their oral health status, generally poor self-care behaviors, and interest in future services.

The clear majority of participants failed to meet recommended oral hygiene recommendations, and most had not visited a dental care professional in more than a year. These findings are not unexpected given that most state-supported quitlines target tobacco users who are of low socioeconomic status—a population that tends to have poor oral health outcomes and more limited access to dental care;[5,27] however, it is noteworthy that

a majority of people were open to receiving an oral health intervention delivered through the quitline. Moreover, groups who are more economically disadvantaged and at higher risk for oral disease were also more likely to be interested in services. Taken together with previous findings that quitline stakeholders are generally supportive of the idea of using tobacco quitlines to promote better oral health,[19] the results suggest that working with tobacco quitlines to offer an integrated oral health intervention is a potentially viable intervention strategy.

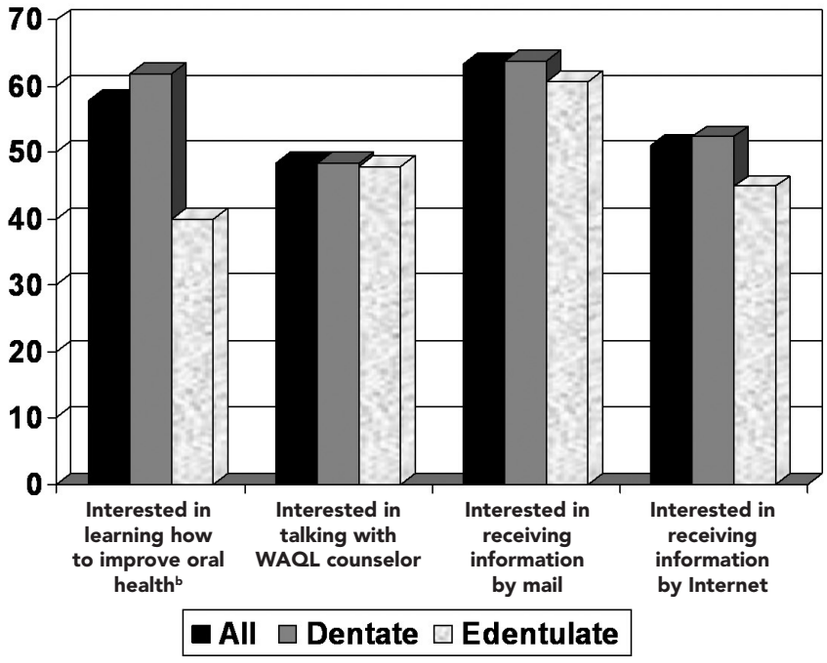
It remains unclear whether brief oral health counseling delivered by tobacco counselors can result in meaningful oral health behavior change, but recent evidence indicates that motivational counseling and cognitive-behavioral interventions can be effective means of changing oral health behaviors.[28–30] Moreover, many behavior changes that can support tobacco cessation (e.g., reduced alcohol intake and use of brushing and flossing as a distraction from cravings) can also benefit oral health, so there is reason to believe that an integrated intervention program could be dually beneficial. Thus, further investigation appears warranted.

**Strengths and limitations**

This study had several strengths, including random sampling of WAQL callers, low demand characteristics (i.e., minimal pressure for respondents to misrepresent their attitudes or behaviors), sample size, and the fact that this was the first survey of its kind to address the issue of oral health and tobacco quitlines.

However, the study was subject to several limitations. One limitation was our inability to compare respondents' oral health attitudes and behavior with that of nonrespondents; however, based on our sampling frame, methodology, and the demographic characteristics of respondents compared with the overall population of WAQL callers, we believe that the current results are generalizable to the broader population of WAQL callers. Another potential limitation was our reliance

**Figure. Interest in oral health promotion services of dentate respondents who were eligible[a] to participate in an oral health survey: Washington State Quitline, June–October 2010**




[a]To be eligible for the survey, callers had to be ≥18 years of age, a current tobacco user, able to read and speak in English, be calling the Washington State Quitline to enroll in services, and provide consent for their contact information to be shared with Group Health Research Institute for the written survey.

[b]Proportion of all respondents, dentate respondents, and edentulate respondents interested in receiving oral health promotion intervention or materials through tobacco quitlines. A significant proportion of respondents were receptive to future services. The comparison of dentate vs. edentulate respondents was significantly different (61.9% vs. 40.0%, odds ratio = 1.70, 95% confidence interval 1.18, 2.44; $p=0.004$). No other comparisons of dentate vs. edentulate respondents were statistically significant.

WAQL = Washington State Quitline

on self-report data; however, people would be expected to overreport rather than underreport their adherence to standard oral health recommendations, such as daily brushing, flossing, and use of professional dental care. As such, we have confidence that the findings confirm the need for intervention in this high-risk population.

## CONCLUSION

Working with state-supported tobacco quitlines is a creative way to reach underserved, high-risk populations for oral disease. Many states limit free services to those with little or no insurance or other specialty groups (e.g., pregnant smokers) who could benefit from this intervention. The present survey suggests that WAQL callers are generally receptive to the concept of an integrated oral health promotion-tobacco cessation program, particularly those who may need an intervention the most. Further research into whether or not this strategy is effective may be warranted.

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# Prevalence, Distribution, and Correlates of Hepatitis C Virus Infection Among Homeless Adults in Los Angeles

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## ABSTRACT

**Objective.** We documented the prevalence, distribution, and correlates of hepatitis C virus (HCV) infection among urban homeless adults.

**Methods.** We sampled a community-based probability sample of 534 homeless adults from 41 shelters and meal programs in the Skid Row area of downtown Los Angeles, California. Participants were interviewed and tested for HCV, hepatitis B, and HIV. Outcomes included prevalence, distribution, and correlates of HCV infection; awareness of HCV positivity; and HCV counseling and treatment history.

**Results.** Overall, 26.7% of the sample tested HCV-positive and 4.0% tested HIV-positive. In logistic regression analysis, independent predictors of HCV infection for the total sample included older age, less education, prison history, and single- and multiple-drug injection. Among lifetime drug injectors, independent predictors of HCV infection included older age, prison history, and no history of intranasal cocaine use. Among reported non-injectors, predictors of HCV infection included older age, less education, use of non-injection drugs, and three or more tattoos. Sexual behaviors and snorting or smoking drugs had no independent relationship with HCV infection. Among HCV-infected adults, nearly half (46.1%) were unaware of their infection.

**Conclusions.** Despite the high prevalence of HCV infection, nearly half of the cases were hidden and few had ever received any HCV-related treatment. While injection drug use was the strongest independent predictor, patterns of injection drug use, non-injection drug use, prison stays, and multiple tattoos were also independent predictors of HCV. Findings suggest that urgent interventions are needed to screen, counsel, and treat urban homeless adults for HCV infection.

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The hepatitis C virus (HCV) is the most common chronic blood-borne viral infection in the United States. Beginning in 1988–1994,[1] the National Health and Nutrition Examination Survey (NHANES), a survey of U.S. households, began estimating prevalence rates for hepatitis C infection in the U.S. general population for those aged 6 years and older. The most recent national prevalence estimate (based on the 1999–2002 NHANES) was 1.6%, or about 4.1 million people.[2] The primary identified means of transmission was through injection drug use. Unfortunately, the NHANES excluded large groups at high risk for HCV infection. A recent article suggested that if high-risk groups that were missed or underrepresented in NHANES (i.e., homeless or incarcerated people, Veterans, health-care workers, and those on long-term dialysis)[3] had been included, a conservative estimate of HCV in the U.S. would have been somewhat higher, at 2.0% or about 5.2 million people.[4,5] These understudied populations that constitute a significant reservoir of HCV infection can provide additional insight into the extent and correlates of HCV infection.

Recent studies suggest that homeless adults in urban areas are at particularly high risk for hepatitis C infection (19%–69%) due to high rates of risky injection drug use.[6–13] Unfortunately, these studies have usually been based on convenience, clinical, or subgroup samples, and findings may not generalize beyond the groups studied.[14]

We documented the prevalence, distribution, and risk factors for HCV infection based on a probability sample of homeless adults. This study fills an important gap in the literature by using a large representative sample of inner-city homeless adults to generate a more accurate estimate of HCV infection in an urban homeless adult population. Further, we documented the high prevalence of "hidden" (i.e., participants were unaware of their infection status) HCV infection in this group and the current unmet need for HCV screening and HCV-specific health services. Findings will inform future intervention and treatment programs aimed at preventing exposure to and transmission of HCV among homeless people and the general population.

## METHODS

For the University of California at Los Angeles (UCLA)/Alcohol Research Group (ARG)/RAND Corporation Homeless Hepatitis Study (known as the UCLA/ARG/RAND Homeless Hepatitis Study), a community-based probability sample of homeless adults was recruited from the Skid Row area in downtown Los Angeles (LA), from June 2003 to February 2004.

### Target population

The target population was adults who experienced homelessness during the previous night. To be eligible, participants had to be ≥18 years of age; have spent the previous night either (*1*) in a public or private shelter or (*2*) on the streets (i.e., in a public or private place not designed for, or ordinarily used as, regular sleeping accommodations for humans);[15] be English-speaking; and demonstrate cognitive competence, assessed as needed.[16]

### Design

We adapted the service-sector approach to probability sampling, which has been used successfully in previous work with homeless populations[17–19] and which reportedly represents the great majority of homeless adults in urban areas (usually 85%–94%).[20–22] We constructed a sampling frame of shelters and free meal programs throughout LA's Skid Row area, which is bounded by four freeways (the Harbor, Santa Monica, Hollywood, and Interstate-5 freeways). We compiled a list of all programs that served homeless adults in the target area. From the list, all shelter and meal programs were selected to constitute the sampling frame. Treatment programs were excluded. The sampling frame consisted of 41 service programs: 19 shelter programs at 10 locations and 22 meal programs at nine locations.

We employed a two-stage representative sampling design. First, we stratified the frame by site and site-use days (i.e., days of the week on which target services were provided) as sampling units. Second, clients were sampled on selected site-use days using sampling strategies that were tailored to each site (either simple random or systematic random sampling). One site (2% of eligible sites) refused to participate.

Of 903 program clients screened for study eligibility, 586 were initially identified as eligible. Among these, 41 refused enrollment, and one could not be subsequently located. Ten were later identified as repeaters, and their second interviews were excluded. The final sample included 534 clients for an interview and blood draw completion rate of 92.7% (534/576). The combined screening and interview response rate was 83.0%.

### Data collection

The RAND Survey Research Group conducted the fieldwork.[23] Interviewers briefly screened each sampled client for eligibility. Data collection took about 90 minutes and included informed consent, structured interview, pretest counseling, and serum collection.

Each participant received $30 cash for completing the interview and serum collection. Participants were then given an appointment for one week later at the

same site to obtain test results. A toll-free telephone number was provided to all participants to receive test results by phone. Participants were originally offered $10 to return for results. Subsequently, the incentive was raised to $25 to increase the return rate. The overall rate of notification of test results, either in person or by phone, was 92%. Participants informed by phone ($n$=3) were not given the second incentive. On average, notification occurred seven days after baseline (median = 7 days, mean = 25 days). Those testing positive for HCV, hepatitis B, or human immunodeficiency virus (HIV) were given appointments for follow-up medical care at one of three specific primary care clinics serving homeless people in the Skid Row area. In addition, all respondents notified in person were given a list of local clinics where they could obtain health care.

**Measures**

***Background measures.*** Baseline survey data were collected through structured face-to-face 60-minute computer-assisted personal interviews (about 400 questions). Biological sex was operationalized by sex attributed at birth. Current homelessness was operationalized by having stayed in a homeless shelter or on the street during the previous night, and chronic homelessness was defined by an accumulation of 12 months or longer spent homeless since 18 years of age. Prison stays and psychiatric hospitalizations, lifetime transfusion of blood or blood products before 1990, and number of tattoos were also assessed.

***Diagnostic measures.*** Lifetime and current (12-month) major mental and substance-use disorders were assessed by selected modules from a computerized version of the Diagnostic Interview Schedule, Version IV (DIS-IV).[24] To reduce respondent burden, a standardized, shortened version of the DIS-IV was used. For each module, questions were asked only until the participant either met minimum criteria for a specific diagnosis or was excluded from the diagnosis. Modules included assessment of major affective disorders (including depression and bipolar disorders), schizophrenia, alcohol use disorders, and drug use disorders. Drug disorders were assessed in aggregate as well as by specific classes of drugs, including opiates, cocaine, amphetamines and other stimulants, sedatives, and hallucinogens.

***Self-reported substance use.*** Alcohol measures included recent frequent heavy drinking ("binge drinking"), defined as five or more drinks at least once per month in the previous 12 months. Drug use measures included lifetime and recent (12-month) use of marijuana, cocaine, ecstasy or other hallucinogens, sedatives and hypnotics, methamphetamine or other stimulants, heroin (alone or combined with other drugs), and other opiates. Mode of use (e.g., injection, "snorting," or smoking) was also assessed. Lifetime injection of illicit drugs (i.e., drugs not prescribed for the user or not used as prescribed) and injections of specific drugs or combinations of drugs were also assessed. Injectors were also asked whether they had ever shared previously used or potentially contaminated injection paraphernalia (including needles or syringes, water for rinsing needles, cotton for filtering drug solutions, or "cookers" [e.g., spoons or bottle caps for dissolving drugs]), or injected drugs in a "shooting gallery" (i.e., a place where injection drug users may congregate, purchase, or inject drugs) or in another place where the participant did not know who else had used the injection paraphernalia. We also assessed history of overdose while using injection drugs (i.e., participant lost consciousness and had to be revived).

Regarding non-injection drug use, questions covered lifetime smoking of crack or any other drugs, intranasal use of cocaine or other drugs (i.e., snorting), and sharing straws for intranasal drug use.

Lifetime pattern of drug use was created as a variable with five categories, which were adapted from the three-category drug-use variable that Armstrong and colleagues used to predict HCV.[2] The five categories in the new variable were mutually exclusive, with participants assigned to the pattern of their most severe drug use. We divided non-injectors into those reporting (*1*) no drug use, (*2*) non-injection drug use (e.g., cocaine, methamphetamine, or hallucinogens) including marijuana, and (*3*) non-injection drug use excluding marijuana. Injection drug use was divided into two subgroups based on the number of different types of drugs ever injected: (*1*) single-drug injection (i.e., the participant only ever injected one specific drug [e.g., only heroin]) and (*2*) multiple-drug injection (i.e., the participant ever injected more than one specific drug [e.g., heroin and cocaine], whether separately or simultaneously [e.g., a speedball]).[18]

Separately, mixed-drug injection identified participants who had ever injected a mixture of two or more drugs.[18,25,26]

***Sexual behaviors and conditions.*** Assessment of lifetime sexual risk behaviors included asking biological males if they had ever had sex of any kind with another man (i.e., men who have sex with men [MSM]). Lifetime sex risk also included sex work (i.e., receiving cash or drugs for sex) and a prior diagnosis of syphilis, gonorrhea, or Chlamydia. Recent (past 12 months) sexual risk behavior included sex with five or more partners.[18]

***HCV history.*** We also assessed histories of counseling, blood testing, and treatment for HCV.

**Blood test measures**

Participants were tested for lifetime infection with HCV. Serum was tested for HCV antibodies using a second-generation enzyme-linked immunosorbent assay (ELISA). Per Centers for Disease Control and Prevention (CDC) recommendation, only ELISA tests with a signal-to-cutoff ratio of <3.8 required confirmation using a supplemental recombinant immunoblot assay (RIBA, 3.0 generation). Among the 155 participants who tested positive, indeterminate, or borderline-negative for HCV on the ELISA test, 20 had signal-to-cutoff ratios <3.8 and required confirmation of HCV positivity with the RIBA test.[27] Fourteen of these participants were confirmed HCV-positive, and six were coded HCV-negative, leaving 149 HCV-positive participants overall. Infectiousness and chronic HCV infection were not assessed.

Lifetime HIV infection was determined by ELISA with confirmation by Western blot testing. Serum was tested for alanine aminotransferase (ALT) as a marker of active liver disease.

**Data analysis**

All analyses were weighted to adjust for each participant's selection probabilities, multiple screenings, and frequency of site utilization. Sample sizes were unweighted. Using SAS®,[28] unadjusted (bivariate) associations between categorical variables and HCV infection status were tested with Chi-square and Fisher's exact statistics for the total sample and separately for injectors and non-injectors. We used odds ratios (ORs) to describe the magnitude of these associations, although the unadjusted ORs may overestimate the magnitude of the associations where HCV is common. Note that ORs do not represent risk ratios here.

To create a core multivariate model of independent predictors of HCV infection, only those variables associated with HCV with two-sided $p$-values <0.15 in unadjusted (bivariate) analyses were entered into a stepwise backward multiple logistic regression. This method was used due to the large number of variables that might be associated with HCV infection relative to the sample size. Four dummy variables representing the mutually exclusive categories of drug-use patterns described previously were forced into the stepwise model: "having injected two or more drugs," "having injected only one drug," "having used non-injection drugs including marijuana," and "having used non-injection drugs excluding marijuana." The reference category was "no reported lifetime drug use." Variables associated with HCV with $p$-values <0.05 were retained in the final multivariate model. Models were similarly constructed for mutually exclusive subgroups of participants who reported either (*1*) lifetime drug injection or (*2*) no lifetime drug injection.

Multicollinearity was found to be a problem in the regression models with two variables: multiple-drug injection (two or more drugs injected at different times or simultaneously) and mixed-drug injection (two or more drugs injected simultaneously). Consequently, both variables were forced into separate but otherwise equal regression models to identify the stronger factor; hence, multiple-drug injection was used for two of the three final logistical regression models (i.e., total sample and injector subsample). We assessed goodness of fit for all three models using the Hosmer-Lemeshow test. We used Stata® to analyze survey data to control for possible cluster effects and to utilize the sampling weights.[29]

## RESULTS

**Sample characteristics**

The majority of the total sample was male (73.6%), black (79.7%), U.S.-born (89.9%), and older than 40 years of age (73.6%) (Table 1). The mean age was 45.8 years (data not shown). Nearly all had completed at least 10 years of education. The majority (70.8%) reported chronic homelessness, and the median aggregated time spent homeless as an adult was 2.2 years (data not shown). About two-thirds spent the previous night on the street, while only one-third were in shelters. Many participants met lifetime diagnostic criteria for major mental disorders (e.g., depression [31.8%] and schizophrenia [7.0%]) and serious substance use disorders (e.g., alcohol dependence [29.7%] and drug dependence [33.2%]).

**Prevalence of HCV infection**

More than one-quarter of the sample (26.7%) tested positive for HCV antibodies, indicating infection during the lifetime (Table 1). Among these participants, 5% had ALT levels that were twice the upper limit of normal, suggesting active liver disease (data not shown).

Among the total sample, 4.0% tested seropositive for HIV, including 0.7% who had tested positive for both HCV and HIV. That is, 18.7% of HIV-infected participants were also infected with HCV, and 2.8% of HCV-infected participants were also infected with HIV (data not shown).

**Table 1. HCV seroprevalence, by risk factor, among urban homeless adults in downtown Los Angeles, California, 2003–2004**

| *Variable* | *Sample* N *(percent)* | *HCV-positive Percent* | *OR (95% CI)* |
|---|---|---|---|
| Total sample | 534 (100.0) | 26.7 | |
| Demographics | | | |
| Age (in years)[a] | | | |
| 18–39 | 137 (26.4) | 10.4 | Ref. |
| ≥40 | 397 (73.6) | 32.5 | 4.15 (2.37, 7.27) |
| Gender[b] | | | |
| Male | 424 (79.7) | 29.4 | 2.18 (1.20, 3.98) |
| Female | 110 (20.3) | 16.0 | Ref. |
| Race/ethnicity | | | |
| White | 71 (12.9) | 25.2 | Ref. |
| Black | 373 (69.6) | 27.0 | 1.10 (2.61, 1.98) |
| Latino/Hispanic | 57 (11.1) | 28.4 | 1.17 (0.54, 2.57) |
| Other | 33 (6.4) | 23.0 | 0.89 (0.34, 2.32) |
| Education[b] | | | |
| ≤9th grade | 53 (9.2) | 46.9 | Ref. |
| ≥10th grade | 481 (90.8) | 24.6 | 0.37 (0.20, 0.69) |
| Veteran | | | |
| Yes | 108 (19.6) | 28.0 | 1.09 (0.66, 1.77) |
| No | 426 (80.4) | 26.3 | Ref. |
| Born in U.S.[c] | | | |
| Yes | 483 (89.9) | 28.1 | 2.41 (1.09, 5.34) |
| No | 51 (10.1) | 14.0 | Ref. |
| Homelessness history | | | |
| In shelter, previous night | | | |
| Yes | 163 (35.2) | 24.6 | 0.85 (0.55, 1.31) |
| No | 27.8 (64.8) | 27.8 | Ref. |
| Chronic homelessness (≥12 months) | | | |
| Yes | 393 (70.8) | 28.0 | 1.24 (0.77, 2.01) |
| No | 149 (29.2) | 23.8 | Ref. |
| Institutional history | | | |
| Prison, lifetime[a] | | | |
| Yes | 154 (28.1) | 41.5 | 2.75 (1.80, 4.20) |
| No | 378 (71.9) | 20.5 | Ref. |
| Psychiatric hospitalization, lifetime | | | |
| Yes | 100 (18.8) | 28.4 | 1.11 (0.69, 1.81) |
| No | 434 (81.2) | 26.3 | Ref. |
| Potential transmission routes | | | |
| Transfusion blood products before 1990[d] | | | |
| Yes | 48 (9.5) | 37.2 | 1.72 (0.94, 3.15) |
| No | 484 (90.5) | 25.6 | Ref. |
| ≥3 tattoos, lifetime[d] | | | |
| Yes | 55 (11.2) | 36.4 | 1.70 (0.96, 3.01) |
| No | 465 (88.8) | 25.2 | Ref. |
| Mental health | | | |
| Major depression, lifetime[e] | | | |
| Yes | 170 (31.8) | 30.6 | 1.17 (0.94, 1.44) |
| No | 356 (68.2) | 24.5 | Ref. |
| Schizophrenia, lifetime[e] | | | |
| Yes | 38 (7.0) | 27.0 | 1.02 (0.70, 1.48) |
| No | 490 (93.0) | 26.7 | Ref. |

*continued on p. 412*

**Table 1 (continued). HCV seroprevalence, by risk factor, among urban homeless adults in downtown Los Angeles, California, 2003–2004**

| *Variable* | *Sample N (percent)* | *HCV-positive Percent* | *OR (95% CI)* |
|---|---|---|---|
| Drugs | | | |
| Drug dependence, lifetime[a,e] | | | |
| Yes | 180 (33.2) | 38.3 | 2.35 (1.58, 3.49) |
| No | 348 (66.8) | 20.9 | Ref. |
| Cocaine dependence, lifetime[c,e] | | | |
| Yes | 164 (29.9) | 34.2 | 1.69 (1.13, 2.55) |
| No | 363 (70.1) | 23.5 | Ref. |
| Amphetamine dependence, lifetime[a,e] | | | |
| Yes | 33 (6.0) | 52.1 | 3.26 (1.58, 6.73) |
| No | 495 (94.0) | 25.1 | Ref. |
| Opiates dependence, lifetime[a,e] | | | |
| Yes | 26 (5.4) | 81.5 | 14.30 (5.45, 37.50) |
| No | 502 (94.6) | 23.5 | Ref. |
| Injection drug use, lifetime[a] | | | |
| Yes | 111 (20.4) | 77.6 | 22.03 (12.97, 39.40) |
| No | 423 (79.6) | 13.6 | Ref. |
| Injection drug use, past 12 months[a] | | | |
| Yes | 12 (2.7) | 79.6 | 11.55 (3.14, 42.51) |
| No | 522 (97.3) | 25.2 | Ref. |
| Mixed-drug injection, lifetime[a,f] | | | |
| Yes | 53 (9.8) | 84.8 | 21.91 (9.90, 48.04) |
| No | 481 (90.2) | 20.3 | Ref. |
| Drug smoker (crack or other drug), lifetime[a] | | | |
| Yes | 361 (67.8) | 32.1 | 2.63 (1.60, 4.33) |
| No | 173 (32.2) | 15.2 | Ref. |
| Intranasal cocaine use, lifetime[a] | | | |
| Yes | 207 (39.4) | 35.9 | 2.15 (1.46, 3.18) |
| No | 327 (60.6) | 20.7 | Ref. |
| Drug use, lifetime[a,g] | | | |
| No drug use | 80 (14.2) | 12.6 | Ref. |
| Non-injection drug use, including marijuana[h] | 297 (57.2) | 11.1 | 0.86 (0.40, 1.86) |
| Non-injection drug use, excluding marijuana[i] | 46 (8.3) | 33.1 | 3.42 (1.36, 8.63) |
| Single-drug injection[j] | 35 (6.5) | 67.6 | 14.44 (5.42, 38.50) |
| Multiple-drug injection[k] | 76 (13.8) | 82.4 | 32.50 (13.16, 80.29) |
| Alcohol | | | |
| Alcohol dependence, lifetime[d,e] | | | |
| Yes | 155 (29.7) | 32.0 | 1.46 (0.97. 2.20) |
| No | 373 (70.3) | 24.4 | Ref. |
| Binge drinking, past 12 months[b] | | | |
| Yes | 221 (42.1) | 32.7 | 1.70 (1.15, 2.50) |
| No | 313 (57.9) | 22.3 | Ref. |

*continued on p. 413*

## Distribution of HCV

***Total sample.*** In bivariate analysis of the total sample (Table 1), HCV prevalence was significantly higher among participants who were male, older (≥40 years of age), less educated, U.S.-born, former prison inmates, and lifetime injectors (especially injectors of mixed drugs). More than half (59.3%) of those with HCV infection disclosed having ever injected drugs, while 40.7% with HCV did not report this well-known HCV risk factor (data not shown).

In the total sample, HCV was also significantly higher among participants who met diagnostic criteria for drug dependence generally and for opiate dependence specifically, and among participants who reported ever smoking crack or other drugs or intranasal use of cocaine. Finally, HCV was significantly higher among MSM, as well as participants with recent binge drinking,

**Table 1 (continued). HCV seroprevalence, by risk factor, among urban homeless adults in downtown Los Angeles, California, 2003–2004**

| *Variable* | *Sample* N *(percent)* | *HCV-positive Percent* | *OR (95% CI)* |
|---|---|---|---|
| Sexual behavior | | | |
| MSM, lifetime (among 424 males reporting)[c] | | | |
| Yes | 79 (17.7) | 39.5 | 1.75 (1.04, 2.94) |
| No | 345 (82.3) | 27.2 | Ref. |
| Sex for cash, lifetime[a] | | | |
| Yes | 115 (21.4) | 40.1 | 2.26 (1.46, 3.50) |
| No | 418 (78.6) | 22.9 | Ref. |
| Sex for drugs, lifetime | | | |
| Yes | 84 (14.7) | 31.1 | 1.30 (0.77, 2.19) |
| No | 449 (85.3) | 25.8 | Ref. |
| Syphilis, lifetime[b] | | | |
| Yes | 48 (8.4) | 43.3 | 2.27 (1.21, 4.28) |
| No | 486 (91.6) | 25.1 | Ref. |
| Gonorrhea, lifetime[b] | | | |
| Yes | 108 (1.9) | 39.4 | 2.10 (1.30, 3.40) |
| No | 426 (80.9) | 23.7 | Ref. |
| Chlamydia, lifetime | | | |
| Yes | 33 (6.1) | 28.4 | 1.12 (0.50, 2.49) |
| No | 498 (93.9) | 26.3 | Ref. |
| ≥5 sex partners, past 12 months | | | |
| Yes | 104 (19.5) | 26.0 | 1.05 (0.64. 1.70) |
| No | 429 (80.5) | 28.4 | Ref. |

Note: Percentages are weighted; sample sizes are unweighted.

[a]$p<0.001$

[b]$p<0.01$

[c]$p<0.05$

[d]$p<0.10$

[e]Assessed with computerized Diagnostic Interview Schedule, Version IV (based on Diagnostic and Statistical Manual of the American Psychiatric Association, Version IV criteria)

[f]Mixed injection drug use (i.e., combined two or more drugs during the same injection)

[g]Categories are mutually exclusive, with participants assigned to their most severe drug-use category.

[h]Non-injection drug user who reported lifetime marijuana use

[i]Non-injection drug user who did not report lifetime marijuana use

[j]Single-drug injector

[k]Multiple-drug injector (i.e., injected more than one drug, at the same time or at different times)

HCV = hepatitis C virus

OR = odds ratio

CI = confidence interval

Ref. = reference group

MSM = men who have sex with men

lifetime syphilis or gonorrhea, and lifetime receipt of cash for sex work. HCV was only marginally higher among people with alcohol dependence and those who reported transfusion of blood products before 1990.

### Injector vs. non-injector subgroups

***Injectors.*** One-fifth of the total sample (20.4%) reported lifetime injection drug use (Table 1). Among injectors, 77.6% tested HCV-positive.

In bivariate analysis of injectors, HCV infection was significantly higher among black vs. white participants (OR=3.10) and among those who were older (OR=5.46) or had a prison history (OR=3.82) (Table 2). HCV was also significantly higher among those who had injected for more than 20 years vs. those who had injected drugs for <20 years. Compared with other injectors, the rate of HCV infection was lower among MSM injectors.

Compared with single-drug injectors, HCV rates were significantly higher among multiple-drug injectors. Bivariate analysis revealed that compared with single-drug injectors, significantly more multiple-drug injectors reported use of drug-injection paraphernalia that someone else had already used, including solutions (44.6% vs. 13.9%, $p<0.01$); water, cookers, or cotton (60.1% vs. 34.6%, $p<0.05$); and borrowed needles or syringes (57.1% vs. 26.6%, $p<0.01$). Compared with single-drug injectors, significantly more multiple-drug injectors also had injected in shooting galleries or in other places where they did not know who else had used the equipment before them (27.6% vs. 7.8%, $p<0.05$). Further, more multiple-drug injectors than single-drug injectors reported overdoses (31.3% vs. 11.0%, $p<0.05$) (data not shown).

***Non-injectors.*** In the non-injector subgroup (Table 2), 13.6% tested positive for HCV. In bivariate analysis among non-injectors, HCV rates were significantly higher among participants who were older and less educated, used non-injection drugs (excluding marijuana), had three or more tattoos, or had a prison history.

### Multivariable analysis of HCV infection

***Total sample.*** Multivariate analysis is presented in Table 3. Pattern of lifetime drug use was associated with HCV infection. Compared with non-drug users in the total sample, multiple-drug injectors had 27.1 times the odds of HCV infection, single-drug injectors had 12.5 times the odds of HCV infection, and users of non-injection drugs (excluding marijuana) had 2.9 times the odds of HCV infection. HCV infection rates for non-injection drug users (including marijuana) did not differ from those who reported no drug use. Other important independent predictors of HCV infection for the total sample included older age, less education, and having been in prison.

While histories of intranasal drug use or smoking of crack or other drugs were significant at the bivariate level for the total sample, neither had an independent relationship with HCV in the multivariate analysis. Similarly, despite significant associations with HCV at the bivariate level, none of the sexual risk behaviors demonstrated an independent association with HCV infection after controlling for other variables.

### Injector vs. non-injector subgroups

***Injectors.*** For the lifetime injector subgroup (Table 3), HCV infection was independently associated with older age and prison history. Among injectors, ever using cocaine intranasally was protective against HCV infection.

In two separate multiple logistic regression models for injectors, neither multiple-drug injection nor mixed-drug injection was significantly associated with HCV infection, perhaps due to the small sample size of injectors.

***Non-injectors.*** In the regression model for the residual group of reported non-injectors (Table 3), use of non-injection drugs (excluding marijuana), three or more tattoos, older age, and less education were each independently associated with HCV infection.

### HCV awareness, testing, counseling, and treatment

Nearly half (46.1%) of HCV-infected participants were not aware of their infection status before we tested them. Rates of previous HCV testing were 35.5% of the total sample, 51.2% of those testing HCV-positive, and 48.9% of lifetime injectors. Most participants had never received counseling about HCV (including 72.6% of the total sample, 65.2% of those testing HCV-positive, and 60.5% of injectors) (data not shown).

Among participants who were aware of their HCV infection (i.e., they reported previous HCV diagnosis and serotested HCV-positive), 39.5% had ever been referred for HCV-related care, 5.2% had ever received HCV-related medical care, and only 3.1% were currently receiving HCV-related medical care.

## DISCUSSION

Since the identification of HCV in 1989[30] and its classification as a leading emerging disease, questions persist about the intensity of its proliferation. Four times as prevalent as chronic HIV infection,[5] HCV has infected an estimated 2.7–3.9 million Americans.[2] HCV is more viable than HIV because it spreads and maintains infectiousness more easily, which contributes to its higher proliferation.[31,32] The primary identified means of transmission historically included injection drug use, blood transfusions or donated organs before 1992, hemodialysis, birth to an infected mother, needlesticks, and unsafe therapeutic injections.[33,34] Other transmission modes have also been implicated, including sexual contact, nonsterile application of tattoos and body piercings, sharing of straws used to inhale cocaine or other drugs, and smoking crack cocaine.[33,35]

### HCV prevalence among homeless people in Skid Row

In this representative community-based sample of homeless adults in the Skid Row area of LA, lifetime prevalence of HCV infection was 26.7%. This rate is comparable with lower estimates reported for U.S. homeless adults based on clinical or convenience samples (19%–69%).[5,7–9,11–13,36] However, it contrasts

**Table 2. HCV seroprevalence among urban homeless adults, by risk factor, stratified by drug injection: downtown Los Angeles, California, 2003–2004**

| | *Injector group* | | | *Non-injector group* | | |
|---|---|---|---|---|---|---|
| *Variable* | N *(percent)* | *HCV Percent* | *OR (95% CI)* | N *(percent)* | *HCV Percent* | *OR (95% CI)* |
| Total sample | 111 (100.0) | 77.6 | | 423 (100.0) | 13.6 | |
| Demographics | | | | | | |
| Age (in years) | | [a] | | | [b] | |
| 18–39 | 92 (15.4) | 47.5 | Ref. | 2,118 (9.3) | 5.4 | Ref. |
| ≥40 | 19 (84.6) | 83.2 | 5.46 (1.83, 16.27) | 7,305 (0.8) | 17.0 | 3.60 (1.56, 8.31) |
| Gender | | | | | | |
| Male | 102 (91.4) | 78.1 | 1.33 (0.30, 5.95) | 7,322 (6.7) | 14.5 | 1.43 (0.70, 2.92) |
| Female | 9 (8.7) | 72.8 | Ref. | 101 (23.3) | 10.6 | Ref. |
| Race/ethnicity | | [b] | | | | |
| White | 21 (20.9) | 66.5 | Ref. | 50 (11.1) | 6.0 | Ref. |
| African American | 73 (65.1) | 86.1 | 3.10 (1.03, 9.35) | 300 (70.7) | 13.1 | 2.35 (0.67, 8.17) |
| Latino/Hispanic | 13 (11.7) | 64.4 | 0.91 (0.22, 3.84) | 44 (11.0) | 18.7 | 3.58 (0.87, 14.65) |
| Other | 4 (3.3) | 25.1 | 0.17 (0.01, 2.12) | 29 (7.2) | 22.7 | 4.58 (1.05, 19.90) |
| Education completed | | | | | [b] | |
| ≤9th grade | 15 (15.6) | 79.1 | Ref. | 388 (7.6) | 30.0 | Ref. |
| ≥10th grade | 74 (84.4) | 77.4 | 0.87 (0.70, 1.09) | 35 (92.4) | 12.3 | 0.33 (0.15, 0.74) |
| Veteran | | | | | | |
| Yes | 26 (20.4) | 92.5 | 4.38 (0.85, 22.49) | 82 (19.4) | 10.7 | 0.71 (0.33, 1.53) |
| No | 85 (79.6) | 73.8 | Ref. | 341 (80.6) | 14.3 | Ref. |
| Born in U.S. | | | | | | |
| Yes | 106 (95.6) | 80.3 | 15.61 (0.66, 147.11) | 377 (88.5) | 13.7 | 1.03 (0.43, 2.48) |
| No | 5 (4.4) | 20.7 | Ref. | 46 (11.5) | 13.3 | Ref. |
| History of homelessness | | | | | | |
| In shelter, previous night | | | | | | |
| Yes | 32 (31.6) | 77.4 | 0.98 (0.38, 2.55) | 131 (36.1) | 12.7 | 0.89 (0.49, 1.60) |
| No | 79 (68.4) | 77.8 | Ref. | 292 (63.9) | 14.1 | Ref. |
| Chronic homelessness, ≥12 months | | | | | | |
| Yes | 83 (73.7) | 80.3 | 1.75 (0.67, 4.57) | 310 (70.0) | 13.8 | 1.04 (0.56, 1.91) |
| No | 28 (26.3) | 70.1 | Ref. | 112 (30.0) | 13.4 | Ref. |
| Institutional history | | | | | | |
| Prison, lifetime | | [b] | | | [c] | |
| Yes | 48 (43.2) | 89.3 | 3.82 (1.32, 11.06) | 106 (24.3) | 19.9 | 1.94 (1.07, 3.51) |
| No | 62 (56.8) | 68.5 | Ref. | 316 (75.8) | 11.4 | Ref. |
| Psychiatric hospitalization, lifetime | | | | | | |
| Yes | 29 (27.9) | 69.9 | 0.56 (0.22, 1.44) | 71 (16.4) | 10.4 | 0.70 (0.31, 1.59) |
| No | 82 (72.1) | 80.6 | Ref. | 352 (83.6) | 14.3 | Ref. |
| Potential transmission | | | | | | |
| Transfusion blood products before 1990 | | | | | | |
| Yes | 18 (14.3) | 86.1 | 1.92 (0.43, 8.60) | 30 (8.2) | 15.5 | 1.17 (0.45, 3.08) |
| No | 93 (85.7) | 76.2 | Ref. | 391 (91.8) | 13.5 | Ref. |
| ≥3 tattoos, lifetime | | | | | [b] | |
| Yes | 12 (12.5) | 70.2 | 0.65 (0.18, 2.32) | 43 (10.9) | 26.7 | 2.64 (1.27, 5.46) |
| No | 94 (87.5) | 78.5 | Ref. | 371 (89.1) | 12.1 | Ref. |
| Mental health | | | | | | |
| Major depression, lifetime[d] | | | | | | |
| Yes | 44 (42.9) | 70.8 | 0.76 (0.48, 1.19) | 126 (29.1) | 15.9 | 1.28 (0.71. 2.31) |
| No | 64 (57.1) | 81.0 | Ref. | 292 (70.9) | 12.9 | Ref. |
| Schizophrenia, lifetime[d] | | | | | | |
| Yes | 8 (9.5) | 80.5 | 1.23 (0.24, 6.23) | 30 (6.5) | 7.5 | 0.49 (0.12, 2.11) |
| No | 101 (90.6) | 76.5 | Ref. | 389 (93.5) | 14.2 | Ref. |

*continued on p. 416*

**Table 2 (continued). HCV seroprevalence among urban homeless adults, by risk factor, stratified by drug injection: downtown Los Angeles, California, 2003–2004**

| | *Injector group* | | | *Non-injector group* | | |
|---|---|---|---|---|---|---|
| *Variable* | N *(percent)* | *HCV Percent* | *OR (95% CI)* | N *(percent)* | *HCV Percent* | *OR (95% CI)* |
| Drugs | | | | | | |
| Drug dependence, lifetime | | | | | | |
| Yes | 63 (57.5) | 76.6 | 0.90 (0.36, 2.24) | 117 (27.0) | 17.5 | 1.51 (0.83, 2.72) |
| No | 46 (42.5) | 78.4 | Ref. | 302 (73.0) | 12.4 | Ref. |
| Cocaine dependence, lifetime[d] | | | | | | |
| Yes | 54 (47.4) | 72.9 | 0.61 (0.25, 1.51) | 110 (25.4) | 15.8 | 1.25 (0.68, 2.31) |
| No | 55 (52.6) | 81.4 | Ref. | 308 (74.6) | 13.1 | Ref. |
| Amphetamine dependence, lifetime[d] | | | | | | |
| Yes | 17 (14.5) | 68.6 | 0.58 (0.19, 1.76) | 16 (3.3) | 31.5 | 3.05 (0.95, 9.75) |
| No | 92 (83.6) | 79.1 | Ref. | 403 (96.7) | 13.1 | Ref. |
| Opiate dependence, lifetime[d] | | | | | | |
| Yes | 22 (21.8) | 91.4 | 3.83 (0.85, 17.30) | 4 (1.2) | 37.2 | 3.81 (0.63, 23.02) |
| No | 87 (78.2) | 73.5 | Ref. | 415 (98.8) | 13.5 | Ref. |
| Injection drug use, past 12 months | | | | | | |
| Yes | 79 (71.2) | 79.6 | 1.14 (0.29, 4.45) | NA | NA | NA |
| No | 32 (28.8) | 77.4 | Ref. | NA | NA | NA |
| Injection drug use ≥20 years | | [b] | | | | |
| Yes | 69 (63.3) | 87.6 | 4.65 (1.78, 12.10) | NA | NA | NA |
| No | 42 (36.7) | 60.4 | Ref. | NA | NA | NA |
| Drug smoker (crack or other drug), lifetime | | | | | | |
| Yes | 101 (89.9) | 79.1 | 2.06 (0.55. 7.67) | 260 (62.2) | 14.7 | 1.28 (0.71, 2.31) |
| No | 10 (10.1) | 64.8 | Ref. | 163 (37.8) | 11.8 | Ref. |
| Intranasal cocaine use, lifetime | | | | | | |
| Yes | 79 (72.6) | 74.1 | 0.43 (0.13, 1.37) | 128 (30.9) | 13.0 | 0.92 (0.50, 1.69) |
| No | 32 (27.4) | 87.1 | Ref. | 295 (69.2) | 13.9 | Ref. |
| Drug use, lifetime[e] | | | | | [c] | |
| No drug use | NA | NA | NA | 80 (17.9) | 12.6 | Ref. |
| Non-injection drug use, including marijuana[f] | NA | NA | NA | 29 (71.8) | 11.1 | 0.97 (0.46, 2.04) |
| Non-injection drug use, excluding marijuana[g] | NA | NA | NA | 46 (10.4) | 33.1 | 3.06 (1.23, 7.63) |
| Single-drug injection[h] | 35 (32.1) | 67.6 | Ref. | NA | NA | NA |
| Multiple-drug injection[i] | 76 (67.9) | 82.4 | 2.25 (0.90, 5.64) | NA | NA | NA |
| Mixed-drug injection, lifetime[j] | | | | | | |
| Yes | 53 (48.3) | 84.8 | 2.29 (0.89, 5.91) | NA | NA | NA |
| No | 58 (51.7) | 70.9 | Ref. | NA | NA | NA |
| Alcohol | | | | | | |
| Alcohol dependence, lifetime[a] | | | | | | |
| Yes | 45 (39.7) | 70.0 | 0.50 (0.20, 1.24) | 110 (27.2) | 17.9 | 1.57 (0.87, 2.83) |
| No | 64 (60.3) | 82.2 | Ref. | 309 (72.8) | 12.2 | Ref. |
| Binge drinking, past 12 months | | | | | | |
| Yes | 65 (59.3) | 74.5 | 0.63 (0.24, 1.61) | 156 (37.7) | 15.9 | 1.35 (0.77, 2.38) |
| No | 46 (40.7) | 82.3 | Ref. | 267 (62.3) | 12.2 | Ref. |

*continued on p. 417*

starkly with the 1.6%–2.0% HCV prevalence estimated for the U.S. general population (in part, the high contrast is exaggerated by the younger age range of the NHANES comparison group [those aged 6 years and older], which includes very low-risk young people).[2–5]

### HCV risk factors

***Injection drug use.*** Consistent with the literature on HCV among general[1,37,38] and homeless[6] populations,[8,10] the strongest independent predictor of HCV infection in this sample was lifetime injection drug use. Similar to the general population,[1] other independent predictors

**Table 2 (continued). HCV seroprevalence among urban homeless adults, by risk factor, stratified by drug injection: downtown Los Angeles, California, 2003–2004**

| | *Injector group* | | | *Non-injector group* | | |
|---|---|---|---|---|---|---|
| *Variable* | N *(percent)* | *HCV Percent* | *OR (95% CI)* | N *(percent)* | *HCV Percent* | *OR (95% CI)* |
| Sexual behavior | | | | | | |
| MSM, lifetime (among males reporting: 102 injectors, 322 non-injectors) | | | | | | |
| Yes | 33 (33.4) | 63.6 | 0.30 (0.11, 0.79) | 46 (13.0) | 20.6 | 1.65 (0.72, 3.75) |
| No | 69 (66.6) | 85.4 | Ref. | 276 (87.0) | 13.6 | Ref. |
| Sex for cash, lifetime | | | | | | |
| Yes | 41 (38.7) | 78.9 | 1.13 (0.45, 2.84) | 74 (17.0) | 17.5 | 1.46 (0.74, 2.90) |
| No | 70 (61.4) | 76.9 | Ref. | 348 (83.0) | 12.7 | Ref. |
| Sex for drugs, lifetime | | | | | | |
| Yes | 30 (25.2) | 70.1 | 0.58 (0.22, 1.54) | 54 (12.0) | 10.2 | 0.70 (0.27, 1.82) |
| No | 81 (74.8) | 80.2 | Ref. | 368 (88.0) | 13.9 | Ref. |
| Syphilis, lifetime | | | | | | |
| Yes | 15 (14.4) | 93.2 | 4.59 (0.62, 34.11) | 33 (6.9) | 16.4 | 1.27 (0.46, 3.53) |
| No | 96 (85.6) | 75.0 | Ref. | 390 (93.1) | 13.4 | Ref. |
| Gonorrhea, lifetime | | | | | | |
| Yes | 41 (37.6) | 83.9 | 1.84 (0.69, 4.92) | 67 (14.3) | 9.6 | 0.63 (0.26, 1.57) |
| No | 70 (42.4) | 73.9 | Ref. | 356 (85.7) | 14.3 | Ref. |
| Chlamydia, lifetime | | | | | | |
| Yes | 12 (9.8) | 64.2 | 0.48 (0.13, 1.83) | 21 (5.1) | 11.3 | 0.81 (0.21, 3.15) |
| No | 98 (90.2) | 78.4 | Ref. | 400 (94.9) | 13.6 | Ref. |
| ≥5 sex partners, past 12 months | | | | | | |
| Yes | 31 (29.6) | 72.4 | 0.66 (0.26, 1.70) | 73 (16.3) | 6.5 | 0.39 (0.14, 1.07) |
| No | 80 (70.4) | 79.8 | Ref. | 349 (83.7) | 15.0 | Ref. |

Note: Percentages are weighted; sample sizes are unweighted. Percentages may sum to >100% due to rounding.

[a]$p<0.001$

[b]$p<0.01$

[c]$p<0.05$

[d]Based on the Diagnostic Interview Schedule, Version IV

[e]Categories are mutually exclusive, with participants assigned to their most severe drug-use category.

[f]Non-injection drug use including marijuana: those who reported lifetime marijuana use and use of other non-injection drugs

[g]Non-injection drug use excluding marijuana: those who reported no lifetime marijuana use but use of other non-injection drugs

[h]Single-drug injector

[i]Multiple-drug injector indicates someone who injected more than one drug, at the same time or at different times.

[j]Mixed injection drug use indicates someone who combined two or more drugs during the same injection.

HCV = hepatitis C virus

OR = odds ratio

CI = confidence interval

Ref. = reference group

NA = not applicable

MSM = men who have sex with men

of HCV among injectors included older age and prison history. Injectors had a much higher HCV prevalence (77.6%) compared with reported non-injectors in this sample (13.6%), and compared with injectors of similar age in the U.S. general population (58%).[2] The rates of injection drug use and HCV among injectors in the sample were similar to those for a general homeless sample.[11] However, the rate of injection drug use in this study was lower compared with previous studies of high-risk homeless subsamples.[6–10,12,13]

***Patterns of injection drug use associated with HCV infection.*** Among the total sample, participants with a lifetime drug-use pattern that included injection of multiple

**Table 3. Results of logistic regression analysis for HCV infection among urban homeless adults in downtown Los Angeles, California, 2003–2004**

| *Characteristic* | *Total sample (n=526) OR (95% CI)* | *Injectors (n=110) OR (95% CI)* | *Non-injectors (n=412) OR (95% CI)* |
|---|---|---|---|
| Age ≥40 years | 4.34 (2.12, 8.88)[a] | 3.64 (1.02, 12.95)[b] | 4.69 (1.97, 11.18)[c] |
| Higher education (≥10 years) | 0.86 (0.75, 0.98)[b] | NA | 0.87 (0.76, 1.00)[b] |
| Prison history | 1.92 (1.10, 3.34)[b] | 4.55 (1.23, 16.85)[b] | |
| ≥3 tattoos, lifetime | NA | NA | 2.75 (1.13, 6.69)[b] |
| Drug-use pattern, lifetime (vs. no drug use)[d] | | | |
| Non-injection drug use, including marijuana[e] | 0.76 (0.33, 1.74) | NA | 0.87 (0.38, 2.01) |
| Non-injection drug use, excluding marijuana[f] | 2.87 (1.02, 8.07)[b] | NA | 3.08 (1.11, 8.54)[b] |
| Single-drug injection[g] | 12.54 (4.00, 39.28)[a] | NA | NA |
| Multiple-drug injection[h] | 27.10 (9.48, 77.46)[a] | NA | NA |
| Intranasal cocaine use, lifetime | NA | 0.26 (0.08, 0.87)[b] | NA |

Note: Percentages are weighted; sample sizes are not weighted. Sample sizes are reduced due to list-wise deletion of missing values.

[a] $p<0.001$

[b] $p<0.05$

[c] $p<0.01$

[d] Categories are mutually exclusive, with participants assigned to their most severe drug-use category.

[e] Those who reported lifetime marijuana use and/or use of other non-injection drugs, but no injection drug use

[f] Those who did not report lifetime marijuana use but reported use of other non-injection drugs

[g] Single-drug injectors only injected one drug during their lifetime.

[h] Multiple drug injectors injected more than one drug during their lifetime, during the same injection or at different times.

HCV = hepatitis C virus

OR = odds ratio

CI = confidence interval

NA = not applicable

drugs (whether injected singly or in combination) had twice the odds of having HCV compared with single-drug injectors.[37] Higher HCV rates among multiple-drug injectors have been reported elsewhere.[39] Increased odds of HCV infection among multiple-drug injectors may be due to more high-risk injection practices (e.g., sharing injection paraphernalia), as reported in the current study.

***Non-injection drug use independently associated with HCV infection.*** Use of non-injection drugs has been found to be associated with HCV infection among the general population.[1,40] For the overall homeless sample and for the non-injector subgroup, HCV infection was independently associated with a lifetime pattern of drug use that excluded injection drugs and marijuana.

Contrary to expectation, however, this finding was apparently not due to smoking (e.g., crack) or "snorting" (inhaling) drugs. In bivariate analysis of non-injectors, HCV was not significantly higher among those who reported these suspected risk behaviors.

The relatively high prevalence of HCV infection among the non-injector subgroup may represent underreported injection drug use, which led to misclassification of injectors as non-injectors and subsequent artificial inflation of HCV infection in the group reporting a lifetime pattern of drug use that excluded injection drugs and marijuana. No findings in this study offer an alternative explanation.

However, in this sample, not all non-injection drug use was associated with HCV. For example, the lifetime pattern of drug use that excluded injection drugs but included marijuana included participants who reported marijuana as their only drug use. This second group of non-injectors was not independently associated with HCV infection.

**Prison history associated with higher HCV rates**

Prison history was an independent predictor of HCV infection among the total sample and among injectors. Increased testing and counseling about HCV and substance use upon prison entry and release into the community are needed as part of HCV reduction efforts.[14]

**Tattoos associated with HCV among non-injection drug users**

HCV infection was 13.6% among non-injection drug users. Controlling for important covariates, non-injection drug participants who reported three or more

tattoos had greater odds of HCV infection than those with fewer or no tattoos. Numerous studies suggest that people with tattoos are at increased risk for HCV,[41–45] although there is controversy about the role of tattoos in HCV transmission.[33,46–48]

**"Hidden" hepatitis C and unmet need for treatment**

This study documented a high rate of hidden HCV infection among homeless adults. That is, nearly half of homeless adults with HCV infection were unaware of their HCV status. Only half of those with HCV infection had ever been tested for HCV.

The lack of awareness of HCV infection can have serious consequences. First, if individuals do not know their HCV infected status, they can inadvertently infect others. Furthermore, most people exposed to HCV in the U.S. general population develop chronic HCV (85%–95%) and never clear the virus from their systems.[49] If unaware of their infections, they will not seek out primary or specialty health care to monitor and treat their HCV, which can lead to long-term risk for serious medical problems (e.g., cirrhosis, end-stage liver disease, liver transplantation, or hepatocellular carcinoma) and even death.[5] Because most HCV-infected injectors in this study first used injection drugs 20 or more years ago, the majority may soon need costly medical care.[14] Studies are needed to identify barriers to testing and treatment of homeless people and to determine the degree to which early screening and appropriate treatment of HCV infection might reduce serious long-term health problems and costs associated with chronic HCV infection.

Only one-quarter of the sample had ever received any counseling or education about the prevention, consequences, and transmission of HCV. Even among those who correctly knew that they were infected, few had received any HCV-related medical care. These findings demonstrate a clear unmet need for prevention, screening, and treatment interventions among this high-risk population.[50,51]

Our findings reinforce the recommendation that clinicians screen (i.e., test) homeless adults for HCV, particularly those reporting a history of injection drug use, a prison stay, unspecified hepatitis, or HIV.[2] Using the CDC-recommended method for HCV screening,[27] only 13% of homeless adults who tested HCV-positive on initial screening with ELISA required the more costly RIBA test for confirmation. Thus, voluntary testing for all homeless adults, especially those at high risk for HCV, should be feasible, even with fiscal constraints.

**Limitations**

This study was subject to several limitations. While HCV, HIV, and ALT status were assessed with blood tests, most measures were based on self-report, which can be subject to recall bias and other measurement errors (e.g., injection drug use may have been underreported due to stigma, possibly inflating the rate of HCV infection among reported non-injectors). Also, sampling error may have resulted from a strategy that targeted only meal and shelter programs; however, previous studies[21,52] suggest that similar sampling frames have captured the great majority (85%–94%) of homeless adults in U.S. urban areas. Additionally, findings may not generalize beyond the population and geographic area studied; however, our sample demographics parallel other rigorous studies of homeless adults in U.S. urban areas.[18,19,53,54] Furthermore, cost constraints prevented blood testing of HCV-positive cases for current HCV infectiousness and the prevalence of chronic HCV. Finally, given the study's cross-sectional design, causal inferences cannot be made about the associations between HCV infection and independent risk factors (e.g., multiple-drug injection, non-injection drug use, prison, or tattoos).

Despite these limitations, as far as we know, this is the first estimate of HCV infection rates among urban homeless adults in the U.S. reported for a population-based probability sample. Previous studies have been largely based on convenience, clinical, or subgroup samples, which have problems with their generalizability to the larger urban homeless population.[13]

## CONCLUSIONS

This and previous studies suggest that U.S. urban homeless adults are at high risk for HCV infection. Findings further suggest that as many as half of those infected with HCV may be unaware of their infection. Homeless adults need interventions that include HCV education, counseling, voluntary testing, and treatment services. HCV prevention and treatment programs could be modeled after successful HIV/AIDS interventions developed for shelters, meal programs, health clinics, substance abuse treatment programs, outreach, and other service programs. If resources are limited, findings suggest that interventions prioritize urban homeless subgroups that are at the highest risk for HCV infection; that is, those with a history of injection drug use, time spent in prison, and multiple tattoos.

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# Implementing a Novel Citywide Rapid HIV Testing Campaign in Washington, D.C.: Findings and Lessons Learned

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## ABSTRACT

**Objectives.** In June 2006, the District of Columbia (DC) Department of Health launched a citywide rapid HIV screening campaign. Goals included raising HIV awareness, routinizing rapid HIV screening, identifying previously unrecognized infections, and linking positives to care. We describe findings from this seminal campaign and identify lessons learned.

**Methods.** We applied a mixed-methods approach using quantitative analysis of client data forms (CDFs) and qualitative evaluation of focus groups with DC residents. We measured characteristics and factors associated with client demographics, test results, and community perceptions regarding the campaign.

**Results.** Data were available on 38,586 participants tested from July 2006 to September 2007. Of those, 68% had previously tested for HIV (44% within the last 12 months) and 23% would not have sought testing had it not been offered. Overall, 662 (1.7%) participants screened positive on the OraQuick® Advance™ rapid HIV test, with non-Hispanic black people, transgenders, and first-time testers being significantly more likely to screen positive for HIV than white people, males, and those tested within the last year, respectively. Of those screening positive for HIV, 47% had documented referrals for HIV care and treatment services. Focus groups reported continued stigma regarding HIV and minimal community saturation of the campaign.

**Conclusions.** This widespread campaign tested thousands of people and identified hundreds of HIV-infected individuals; however, referrals to care were lower than anticipated, and awareness of the campaign was limited. Lessons learned through this scale-up of population-based HIV screening resulted in establishing citywide HIV testing processes that laid the foundation for the implementation of test-and-treat activities in DC.

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District of Columbia (DC) surveillance data indicate that the city has a severe and generalized human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS) epidemic, with an HIV/AIDS prevalence of 3.2% and the highest AIDS case rate in the United States (148.1 cases per 100,000 population in DC compared with 12.5 cases per 100,000 population in the U.S.).[1,2]

In September 2006, the Centers for Disease Control and Prevention (CDC) issued revised HIV testing recommendations for health-care settings. These guidelines recommended routine screening of people in all health-care settings and screening of those at high risk for infection on an annual basis.[3]

In an effort to increase testing in advance of the release of the revised CDC recommendations, in June 2006 the DC Department of Health HIV/AIDS Administration (DCDOH/HAA) launched a citywide rapid HIV screening campaign called "Come Together DC—Get Screened for HIV." During the previous year, 2005, DCDOH funded a limited number of community-based, HIV counseling and testing, and clinical sites to conduct targeted rapid HIV testing using Orasure®, fingersticks, and venipuncture. Approximately 20,000 publicly funded HIV tests were conducted in 2005 (Personal communication, Nestor Rocha, DCDOH, October 2008).

As one of the first cities in the U.S. to attempt to establish processes and systems to implement routine testing citywide, DC launched its campaign with three primary goals for raising awareness regarding DC's HIV epidemic: (*1*) reinvigorating the city's response and reaching out to the entire population to stop the spread of HIV, (*2*) routinizing HIV screening in both medical and community health-care settings, and (*3*) reducing HIV transmission by identifying and linking to care and treatment newly diagnosed HIV-positive people and encouraging people living with HIV to make healthy decisions regarding their behaviors.[4]

Through a public health-academic partnership between The George Washington University (GWU) Department of Epidemiology and Biostatistics and the DCDOH/HAA, data collected on people tested through the campaign were analyzed. The objectives of the analysis were to describe people being tested through the campaign, identify potential factors associated with screening HIV-positive, and determine the level of community saturation regarding the campaign among DC residents.

## METHODS

The DCDOH conducted outreach to public, private, and community-based organizations, including both medical and nonmedical providers, to engage them in the use of rapid HIV testing. Social marketing for the campaign included street outreach, media advertisements, and several public events that aimed to publicize the campaign. OraQuick® ADVANCE™ rapid HIV tests (OraSure Technologies, Bethlehem, Pennsylvania) were procured through CDC and extensively distributed free of charge to organizations previously conducting HIV screening, as well as those new to conducting HIV screening. The OraQuick ADVANCE rapid HIV test is a Food and Drug Administration-approved, Clinical Laboratory Improvement Amendments-waived rapid HIV screening test that screens for HIV-1 and HIV-2 in oral fluid, blood, and plasma and has a specificity of 99.8%.[5–8]

All sites receiving test kits were trained by OraSure Technologies, free of charge, on how to properly administer and interpret the test. Participating testing sites were encouraged to implement the CDC recommendations including removing the requirement for pretest counseling and using the opt-out testing approach. For all people screening HIV-positive, referrals for confirmatory testing and referrals for HIV care and treatment and/or prevention were to be made by staff at the testing site. Furthermore, in addition to already existing HIV testing and reporting requirements, participating sites were asked to collect data on each person tested through the campaign through an anonymous standard client data form (CDF).

A mixed-methods approach using quantitative and qualitative data-collection methodologies was employed to assess the extent to which the campaign's goals had been achieved. Data collection for campaign participants involved completion of CDFs by testing staff while participants awaited their rapid HIV test results. The form collected participant demographic information, testing venue, previous testing history, reason for testing, and test result. Data for each test administered were collected from July 2006 through September 2007 and entered into a Microsoft® Access database. Analysis of quantitative data was conducted using univariate, bivariate, and multivariable statistical analyses in SAS® version 8.0.[9] We conducted logistic regression to identify factors potentially associated with testing preliminary positive (PP). We controlled for possible confounders including testing site, gender, race/ethnicity, age group, previous HIV testing, time of last HIV test, request for test had it not been offered, and reason for testing. We considered a $p$-value of $\leq 0.05$ to be statistically significant.

Qualitative methods involved assessing community perceptions of the campaign, including saturation of the social marketing campaign. Data were obtained

through three focus groups of DC residents; one session was with females, another was with males, and one was a mixed group of males and females. Each group of participants convened for two sessions. Participants were recruited from venues through flyers, community outreach workers, and general street recruitment and provided informed consent prior to participation. The focus groups were conducted in a sequential fashion and designed to take advantage of participants' networks and engagement in the community, thereby obtaining perspectives of others in their networks and communities. We developed a focus group guide that elicited information about general health knowledge, HIV knowledge, knowledge regarding HIV testing, and, specifically, the testing campaign. After the initial focus group, participants were given instructions asking them to discuss HIV in general and the testing campaign specifically with friends, family members, and associates and to then report back on these conversations during the subsequent focus group. Focus groups were tape-recorded, transcribed, and entered into ATLAS.ti qualitative data analysis software for thematic coding and analysis.[10]

## RESULTS

### Client data forms

From July 2006 to September 2007, HAA received 38,586 completed CDFs. Although 38,586 CDFs were analyzed, they may have represented people who were tested more than once during this time period. However, as this could not be determined due to the anonymous nature of the data collection, we referred to characteristics documented on each CDF form as being attributed to a "participant." Based on the receipt of CDFs, the highest proportion of tests (31.4%) was conducted through the DC Department of Corrections (DCDOC) Central Detention Facility (Table 1). Of completed CDFs, 75.1% were non-Hispanic black, 62.0% were male, and the mean age was 34.9 years (standard deviation [SD] = 12.97; median = 35.0 years; range: 14–84) (data not shown).

When asked about previous HIV testing, 68.3% of participants reported having been previously tested for HIV prior to the test that was conducted through the campaign. Of the 26,356 participants reporting a history of prior HIV testing, 43.6% had been tested within the last 12 months (Table 1). Among those who had tested previously, 1.0% stated that they were already aware of their HIV-positive status (data not shown).

Almost one-third of participants (31.3%) indicated that they would not have requested or were unsure if they would have had an HIV test had it not been offered

**Table 1. Characteristics of HIV testing campaign participants: Washington, DC, July 2006–September 2007 (*n*=38,586)[a]**

| *Characteristic* | N *(percent)* |
|---|---|
| Testing site | |
| DC Department of Corrections | 12,122 (31.4) |
| HIV counseling and testing site | 8,818 (22.9) |
| Hospital emergency department | 5,941 (15.4) |
| Sexually transmitted disease clinic | 3,627 (9.4) |
| Hospital, other | 2,497 (6.5) |
| Community-sponsored health event | 794 (2.1) |
| Primary physician | 297 (0.8) |
| Other | 3,296 (8.5) |
| Undetermined/no response | 1,194 (3.1) |
| Gender | |
| Male | 23,926 (62.0) |
| Female | 13,604 (35.3) |
| Transgender | 85 (0.2) |
| Unknown | 971 (2.5) |
| Race/ethnicity | |
| Non-Hispanic black | 28,962 (75.1) |
| Non-Hispanic white | 4,687 (12.2) |
| Hispanic | 3,176 (8.2) |
| Other/unknown | 1,761 (4.6) |
| Age group (in years) | |
| 14–17 | 1,233 (3.2) |
| 18–24 | 8,547 (22.2) |
| 25–34 | 9,159 (23.7) |
| 35–44 | 7,791 (20.2) |
| 45–54 | 6,264 (16.2) |
| ≥55 | 2,894 (7.5) |
| Unknown | 2,698 (7.0) |
| State of residence | |
| DC | 27,611 (71.6) |
| Maryland | 5,281 (13.7) |
| Virginia | 1,727 (4.5) |
| West Virginia | 19 (0.1) |
| Unknown/other | 3,948 (10.2) |
| Ever tested for HIV | |
| Yes | 26,356 (68.3) |
| No | 7,171 (18.6) |
| Unknown | 5,059 (13.1) |
| Timing of last HIV test among those with previous testing history | |
| Within the last year | 11,487 (43.6) |
| Between one and two years ago | 5,077 (19.3) |
| More than two years ago | 4,592 (17.4) |
| Unknown interval since last test | 5,200 (19.7) |
| Would have requested an HIV test at visit had it not been offered | |
| Yes | 16,290 (42.2) |
| No | 9,037 (23.4) |
| Not sure | 3,038 (7.9) |
| No response | 10,221 (26.5) |

*continued on p. 425*

**Table 1 (continued). Characteristics of HIV testing campaign participants: Washington, DC, July 2006–September 2007 (*n*=38,586)[a]**

| *Characteristic* | N *(percent)* |
|---|---|
| Reason for testing[b] | |
| Offered by doctor | 11,013 (27.7) |
| To ensure I am negative | 10,774 (27.1) |
| Required to get tested | 5,482 (13.8) |
| Tested on a regular basis | 3,494 (8.8) |
| Worried been exposed to HIV | 2,912 (7.3) |
| Print, radio, or television advertisement | 1,572 (4.0) |
| Other | 4,494 (13.6) |

[a]Of those completing a client data form

[b]Participants were able to indicate more than one reason. Percentages are calculated out of total number of reasons given (*n*=39,759).

HIV = human immunodeficiency virus

DC = District of Columbia

at the visit. The most commonly reported reasons for obtaining an HIV test were because it was "offered by doctor" (27.7%) and "to ensure I am negative" (27.1%). Almost 14% of participants stated that they were tested because they perceived it was required by insurance, military, court order, or another agency. Of people who indicated this perception as their primary reason for testing, 92.1% were tested as part of the DCDOC policy to provide opt-out screening of inmates upon entry and release from the DCDOC Central Detention Facility (data not shown).

**Preliminary positive participants**

Of the 38,586 CDFs collected, 98.3% of HIV tests (*n*=37,924) were negative, indeterminate, or did not indicate a result on the form; 1.7% (*n*=662) of tests were PP for HIV (Table 2). Based on self-reported information from the CDF, 173 (26.1%) of these participants were previously aware of their HIV infection, resulting in 489 (73.9%) potentially newly identified HIV infections (data not shown). Due to the inability to confirm participants' self-reported HIV status, the results presented include all 662 PP tests. The proportion of those screening positive was highest at the DCDOC (2.2%), all hospital sites (i.e., emergency department and other hospital sites) (5.2%); and HIV counseling, testing, and referral (CTR) sites (1.8%), with hospitals being three times more likely to identify PP participants compared with the DCDOC (Table 2). Collectively, DCDOC, HIV CTR, emergency department, and other hospital sites accounted for 85.6% of all PP participants identified. Eighty-six percent of PP participants were non-Hispanic black, 65.1% were male, 48.6% were aged 25–44 years, and 74.2% were DC residents.

As shown in Table 2, in the adjusted analysis, transgender participants were more than 11 times more likely than males to test PP (adjusted odds ratio [AOR] = 11.13, 95% confidence interval [CI] 4.80, 25.74), non-Hispanic black people were 67% more likely than white people to test PP (AOR=1.67, 95% CI 1.09, 2.54), and Hispanic people were 56% less likely than non-Hispanic white people to test PP (AOR=0.44, 95% CI 0.20, 0.96). Those aged 14–24 years were significantly less likely to test PP than those who were aged 35–44 years (AOR for those aged 14–17 years = 0.14, 95% CI 0.05, 0.39; AOR for those aged 18–24 years = 0.41, 95% CI 0.30, 0.58).

Among the 662 PP participants, 100 (15.1%) reported that this was their first ever HIV test, while 511 (77.2%) reported having previously been tested for HIV. Among those who knew when they had last been tested, 151 (40.7%) were tested within the past year. Approximately 37% of participants reported their reason for testing was because the test was offered by a doctor or other health-care provider, and 39.0% of those testing PP responded that they either would not have been tested or were unsure that they would have requested a test had it not been offered by the provider. After adjusting for all other variables, those who tested PP were 40% more likely than those tested within the last year to report that this was their first ever HIV test (AOR=1.40, 95% CI 1.03, 1.90) and two times more likely to have been tested more than two years prior (AOR=2.11, 95% CI 1.60, 2.78). PP participants were 24% more likely to have not requested an HIV test during the visit had it not been offered (AOR=1.24, 95% CI 1.01, 1.52) than those who would have requested an HIV test. PP participants were 30% less likely to have been tested to ensure that they were HIV-negative (AOR=0.70, 95% CI 0.51, 0.94) than those who only tested because the test was offered by a doctor (Table 2).

As part of the DCDOH memorandum of understanding, participating organizations were required to refer PP participants to follow-up care for confirmatory testing and to make appropriate care and treatment and/or prevention recommendations. Among the 83% (*n*=551) of participants testing PP for whom referral information was available, 47.0% (*n*=259) were documented as having received a referral for care and treatment, 21.1% (*n*=116) documented a referral for prevention services, and 11.6% (*n*=64) documented that a referral was made for all three services. For 20.3% (*n*=112) of PP participants, no referral was made; however, reasons for the lack of referrals were

**Table 2. Characteristics of HIV testing campaign participants (*n*=38,586), by test result and adjusted odds of testing preliminary positive: Washington, DC, July 2006–September 2007**

| *Characteristic* | *Preliminary positive result* N *(percent)* | *Negative, indeterminate, or unknown test result* N *(percent)* | *AOR (95% CI)*[a] |
|---|---|---|---|
| Total | 662 (100.0) | 37,924 (100.0) | |
| Testing site | | | |
| DC Department of Corrections | 261 (2.2) | 11,861 (97.8) | Ref. |
| HIV counseling and testing site | 155 (1.8) | 8,663 (98.2) | 1.27 (0.89, 1.81) |
| Hospital emergency department | 63 (1.1) | 5,879 (98.9) | 0.64 (0.39, 1.03) |
| Sexually transmitted disease clinic | 30 (0.8) | 3,597 (99.2) | 0.57 (0.34, 0.95) |
| Hospital, other | 88 (4.1) | 2,034 (95.9) | 3.22 (2.26, 4.58)[b] |
| Community-sponsored health event | 5 (0.6) | 789 (99.4) | 0.35 (0.09, 1.46) |
| Primary physician | 5 (1.7) | 292 (98.3) | 0.89 (0.32, 2.49) |
| Other | 40 (1.2) | 3,256 (98.8) | 0.89 (0.57, 1.40) |
| Unknown | 15 (1.3) | 1,179 (98.7) | NA |
| Gender | | | |
| Male | 431 (1.8) | 23,495 (98.2) | Ref. |
| Female | 202 (1.5) | 13,402 (98.5) | 0.91 (0.73, 1.12) |
| Transgender | 9 (10.6) | 76 (89.4) | 11.13 (4.80, 25.74)[b] |
| Unknown | 20 (2.1) | 951 (97.9) | NA |
| Race | | | |
| Non-Hispanic black | 567 (2.0) | 28,395 (98.0) | 1.67 (1.09, 2.54)[b] |
| Non-Hispanic white | 52 (1.1) | 4,635 (98.9) | Ref. |
| Hispanic | 22 (0.7) | 3,154 (99.3) | 0.44 (0.20, 0.96)[b] |
| Other | 9 (0.9) | 1,049 (99.1) | 0.57 (0.20, 1.64) |
| Unknown | 12 (1.7) | 691 (98.3) | NA |
| Age group (in years) | | | |
| 14–17 | 5 (0.4) | 1,228 (99.6) | 0.14 (0.05, 0.39)[b] |
| 18–24 | 83 (1.0) | 8,464 (99.0) | 0.41 (0.30, 0.58)[b] |
| 25–34 | 152 (1.7) | 9,007 (98.3) | 0.92 (0.70, 1.19) |
| 35–44 | 170 (2.2) | 7,621 (297.8) | Ref. |
| 45–54 | 148 (2.4) | 6,116 (97.6) | 1.15 (0.89, 1.49) |
| ≥55 | 62 (2.1) | 2,832 (97.9) | 0.96 (0.67, 1.38) |
| Unknown | 42 (1.6) | 2,656 (98.4) | NA |
| Ever tested for HIV before | | | |
| Yes | 511 (1.9) | 25,845 (98.1) | NA |
| No | 100 (1.4) | 7,071 (98.6) | NA |
| Unknown | 51 (1.0) | 5,008 (99.0) | NA |
| Timing of prior HIV test | | | |
| First ever test | 100 (1.4) | 7,071 (98.6) | 1.40 (1.03, 1.90)[b] |
| Within the last year | 151 (1.3) | 11,336 (98.7) | Ref. |
| Between one and two years ago | 84 (1.7) | 4,993 (98.3) | 1.19 (0.87, 1.62) |
| More than two years | 136 (3.0) | 4,456 (97.0) | 2.11 (1.60, 2.78)[b] |
| Unknown interval since last test | 140 (2.7) | 5,060 (97.3) | 1.89 (1.42, 2.52)[b] |

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not documented on the CDFs. Referral rates to care, treatment, and/or prevention were highest among hospitals (93.2%) and primary care physicians (100%) and lowest among the sexually transmitted disease (STD) clinic (6.7%), emergency departments (39.7%), community health events (40.0%), and the DCDOC (59.4%) (data not shown).

**Qualitative findings**

To assess community perceptions and saturation of the campaign, three focus groups were held: a male focus group of 13 participants, a female group of 10 participants, and a mixed-gender group of 14 participants. Among the 37 participants, 36 were non-Hispanic

**Table 2 (continued). Characteristics of HIV testing campaign participants (*n*=38,586), by test result and adjusted odds of testing preliminary positive: Washington, DC, July 2006–September 2007**

| *Characteristic* | *Preliminary positive result* N *(percent)* | *Negative, indeterminate, or unknown test result* N *(percent)* | *AOR (95% CI)*[a] |
|---|---|---|---|
| Would have requested an HIV test at visit had it not been offered | | | |
| Yes | 264 (1.6) | 16,026 (98.4) | Ref. |
| No/unsure | 258 (2.1) | 11,817 (97.9) | 1.24 (1.01, 1.52)[b] |
| Unknown | 140 (1.4) | 10,081 (98.6) | NA |
| Reason for testing[c] | | | |
| Offered by doctor | 243 (2.2) | 10,770 (97.8) | Ref. |
| To ensure I am HIV negative | 129 (1.2) | 10,645 (98.8) | 0.70 (0.51, 0.94)[b] |
| Required to get tested | 110 (2.0) | 5,372 (98.0) | 1.13 (0.82, 1.56) |
| Tested on a regular basis | 45 (1.3) | 3,449 (98.7) | 0.79 (0.48, 1.28) |
| Worried been exposed | 81 (2.8) | 2,831 (97.2) | 1.35 (0.87, 2.08) |
| Print, radio, television advertisement | 16 (1.0) | 1,556 (99.0) | 0.56 (0.28, 1.13) |
| Other | 112 (2.6) | 4,211 (97.4) | 1.26 (0.92, 1.73) |

[a]Adjusted for all other variables in the model. Due to the large number of missing/unknown responses, these were excluded in the model as indicated by NA. Due to strong correlation between the "ever HIV tested" and "timing of prior HIV test" categories, the "ever HIV tested" category was also excluded from the adjusted model.

[b]$p \leq 0.05$

[c]Participants were able to indicate more than one reason for getting tested.

HIV = human immunodeficiency virus

DC = District of Columbia

AOR = adjusted odds ratio

CI = confidence interval

Ref. = reference group

NA = not applicable

black, 17 had graduated high school or had a general equivalency diploma, two had graduated college, the mean age was 41.8 years (SD=12.4, range: 18–66), and 33 had been tested for HIV. The second focus group meeting for each group was held within two weeks of the initial group meeting, and 94% of participants attended the second meeting. Sample quotes from participants are shown in the Figure.

Focus group participants recognized HIV as a significant problem in DC. Thematic analysis demonstrated that although participants were aware of high-risk behaviors that place people at increased risk for HIV, they believed the community was not sufficiently talking about HIV. There was also discussion concerning the continued stigma and lack of education about the disease.

Participants had mixed perspectives regarding the barriers to HIV screening in DC. Fear of testing positive was the one issue that emerged during each focus group discussion as a primary obstacle for HIV screening and was identified as a barrier among all demographic groups. Other barriers mentioned included perceptions about not being at risk for HIV; lack of money, transportation, and education; inadequate or no health insurance; and other cultural as well as structural barriers.

Efforts to encourage and support screening in the community were also explored. Participants identified the ease of rapid testing and quick turnaround for obtaining results as incentives for testing. Participants also felt that HIV testing should be a part of any medical examination, similar to getting one's vital signs checked.

Focus group participants were asked to discuss HIV and the DC testing campaign when they returned to their communities. Participants' responses suggested there was minimal community saturation about the campaign. Among the few that had heard about the campaign, they reported seeing advertisements on buses and billboards, and hearing about it on the radio, local news, and from neighbors and community-based organizations. However, most of the participants and the people they spoke with in the community had not heard about the campaign.

The participants demonstrated awareness of DC's HIV/AIDS epidemic and had suggestions for improving awareness overall and for future campaign efforts. Suggestions included identifying people to serve as role models (e.g., those living with HIV/AIDS) and increasing advertisements and providing statistics about HIV/AIDS in the community. Participants felt that the current campaign efforts would raise awareness, stimulate discussions about HIV, and help people realize that their communities were directly affected by the illness.

**Figure. Key focus group findings and sample quotes regarding the Washington, DC, routine HIV testing campaign: July 2006–September 2007**

| *Theme/subject* | *Focus group quotes* |
|---|---|
| Perceptions of HIV in the community | You'd be surprised at how long this thing has been around; you'd be surprised at how little so many people know. |
| | A lot of the youths don't talk about it and they think it's . . . you can't talk about it because it's . . . yeah, taboo. . . . But if they find out one of their buddies got it, they label them and they don't talk about it. |
| | A lot of people are blind to the fact about this disease and how you can catch it, so education is a big part. |
| Barriers to HIV screening | When the stigma first came out in this thing, everybody looked at the thing as a killer. Everybody looked at this thing as a gay disease. . . . So if you straight, you don't think you got it. If you don't use [intravaneous drugs] you don't think you got it, but you don't know what your partner or your multitude of partner[s] have. |
| | Another thing about testing, some people [are] scared to get tested because they don't think or they don't know about the medication that could slow it down. . . . They just think soon as you get it you just die. |
| | The real fear comes from within because you know within yourself, if you're true to yourself, then you know that you [have] done . . . everything to get it. That's where the real fear comes from. |
| Community support for HIV screening | They got a thing they just rub [oral swab] . . . and whatever they do with it after that, they come back with the results in 20 minutes. So you know right there on the spot. You don't [have] to draw . . . blood and have it sent away and wait two, three weeks worrying yourself to death and having nightmares. |
| | But I think it would be great if it could go along with the vital signs and with the [consent] explaining your results [and having something] tangible when you leave there. |
| | There should be a[n] HIV testing date every month so communities can become familiar with the project. |
| Community saturation of campaign | I first heard about [the campaign] through my neighbor in Ward X community. I just heard that "Come Together DC" is a movement for our community people to come together and get tested for HIV and AIDS to encourage us to receive education on the disease. |
| | They heard it from friends and printed on the bus and around the hospital. |
| | Well, I had a conversation with a friend of mine—she also said she [had] never heard of [the campaign]. |
| Suggestions for improving HIV/AIDS awareness and future campaign efforts | I think . . . this kind of campaign at least stimulates discussion among people that hopefully, over time, you know, progress[es] to change, and attitudes change, and there's just more . . . understanding about what this disease is and how it impacts . . . and how . . . no one is sort of exempt from being impacted [in] some way by the virus. |
| | If you have people who have AIDS out there and they don't mind talking about it, then why not? |
| | More advertisement, AIDS awareness, and I guess more commercials on the TV about the seriousness of the disease. |

DC = District of Columbia

HIV = human immunodeficiency virus

AIDS = acquired immunodeficiency syndrome

## DISCUSSION

The results of this evaluation demonstrate that the "Come Together DC—Get Screened for HIV" campaign resulted in HIV screening and data collection for almost 40,000 people from throughout the DC metropolitan area, and potentially identified hundreds of individuals with previously undiagnosed HIV infection. These data suggest that the campaign's goals—to raise awareness regarding the HIV epidemic, to routinize screening, and to identify previously unrecognized infections—were in part achieved.

Implementation of the CDF allowed essential information to be collected about those getting screened, testing behaviors, motivations for testing, and referral patterns among campaign participants. A screening positivity rate of approximately 2%, with the majority of positives identified among non-Hispanic black males and females, was consistent with rates observed through other screening initiatives.[11–14] In addition, the high prevalence observed at the DCDOC Central Detention Facility, at a local emergency department, and at CTR sites underscores the importance of conducting screening in both medical and nonmedical settings.[15] Furthermore, implementation of testing in an environment such as the DCDOC, where people's movements in and out of the system are more controlled, allowed for the identification of many infected people.

Results from this analysis reinforce the CDC approach of non-risk-based opt-out screening, as the DC citywide testing campaign did not collect risk information and almost one-third of PP participants would not have sought testing had it not been offered by a health-care provider.[3] Although participants reported high rates of annual HIV testing, given the high prevalence rates, non-risk-based opt-out testing, in conjunction with routine targeted risk-based screening, may assist in identifying those people who are hesitant to seek testing, perceive themselves at low risk, or are perceived as low risk by health-care providers and who may otherwise go undiagnosed.[16–18]

Although the campaign tested thousands of people, documented referrals were lower than expected, with slightly fewer than half of those screening PP having documentation of a referral for care and treatment. This low rate of linkage, particularly among new HIV testing partners, represents a significant missed opportunity to engage infected people in care and secondary prevention. Previous studies have shown that linkages to confirmatory testing and entry into care present a distinct challenge when rapid testing is employed in nontraditional settings.[16,19–21]

Qualitative data revealed that although HIV was recognized by community members as a serious health threat in DC, there was persistent stigma associated with the disease. Despite several public events to launch and promote the campaign, these data also showed that there was minimal community saturation and awareness of the campaign, despite overall acceptability of routine HIV testing among DC residents. This qualitative approach provides an important addition to the quantitative data in its ability to characterize knowledge, attitudes, and perceptions that are difficult to elicit through close-ended questions. Importantly, these qualitative findings highlighted community buy-in regarding routine screening and the need for individuals to take personal responsibility to advocate for screening.

Through lessons learned from this analysis, the DCDOH has modified its organizational processes and logistics and tailored messages to the patient and provider communities concerning the importance of routine HIV testing. Changes to routine testing approaches include use of a unique identifier to collect data so that analysis of testing rates and characteristics of testers can occur at the individual level; identifying community HIV providers who are willing to conduct the initial HIV care evaluation inclusive of confirmatory testing within 24–72 hours of testing PP, known as the Red Carpet Entry Program; establishing navigator programs to assist in linking people to HIV care and treatment; and requiring documentation of linkage into care, including confirmatory testing among those screening positive, with confirmation of such through laboratory reporting and surveillance data.

In an effort to increase awareness of routine testing, social-marketing initiatives have been designed by the DCDOH to encourage residents to know their status, know their partner's status, and begin the dialogue regarding reducing HIV risk behaviors (e.g., with consistent condom use). Public media campaigns focus on empowering patients to ask for the test at medical visits and encourage providers to conduct routine opt-out testing for all patients. For those people initially refusing an HIV test, providers are encouraged to revisit testing during the clinical examination. In addition, if a person is identified as HIV-infected, identification and testing of sexual partners is also routinely offered.

### Limitations

There were several limitations to the approaches used in this analysis. First, because the CDF was anonymous, it is likely that data were collected on participants who were tested more than once through the campaign and would therefore have been counted multiple times in the analysis. Second, although the OraQuick ADVANCE rapid test is a highly sensitive and specific screening

tool for HIV detection, its use alone is not diagnostic of infection.[5,22,23] Thus, all individuals testing PP on the rapid test should have been referred for confirmatory testing and, if confirmed positive, referred for care, treatment, and prevention. Lastly, although we accounted for it in our quantitative analysis, we had a substantial amount of missing data that may have limited the interpretation and generalizability of our findings. However, our overall findings are consistent with the epidemiologic profile of HIV in DC.

## CONCLUSIONS

The DC campaign, "Come Together DC—Get Screened for HIV," was one of the first in the U.S. to attempt to systematize and implement routine testing at a citywide level, as recommended by CDC in 2006. Our results suggest that centrally supported rapid HIV screening activities at the DCDOH, coupled with acceptability at the facility level and demonstrated client acceptance, can galvanize communities to fight HIV. Since 2006, other cities including the Bronx (New York), Miami (Florida), and Oakland (California) have also implemented citywide HIV testing initiatives.[24–26] Serving as the foundation for the scale-up of routine population-based HIV screening in DC, the campaign has resulted in the selection of DC as one of the Testing and Linkage to Care Plus study intervention communities. The study includes implementation of community-level routine testing, as well as enhanced linkage to care and treatment.[27] Lessons learned from this campaign may provide useful information as other cities expand their routine rapid testing initiatives, while taking into consideration establishment of community partnerships, adequacy of referral systems, and the balance between targeted and routine screening.

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All protocols and materials were approved by the GWU and DCDOH Institutional Review Boards prior to study implementation.

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# Provision of Test Results and Posttest Counseling at STD Clinics in 24 Health Departments: U.S., 2007

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## ABSTRACT

**Objective.** We determined the demographic and HIV test characteristics of tests conducted in CDC-funded sexually transmitted disease (STD) clinics with provision of test results and posttest counseling.

**Methods.** We used CDC's HIV Counseling and Testing System data from 2007 for the 24 U.S. health departments that reported test-level data from STD clinics. We calculated and analyzed newly identified HIV positivity and the percentage of tests with provision of test results and posttest counseling (provision of posttest counseling), by demographic and HIV-related characteristics.

**Results.** Of 372,757 tests conducted among people without a previous HIV diagnosis by self-report, provision of posttest counseling was documented for 191,582 (51.4%) HIV tests overall and 1,922 (71.2%) newly identified HIV-positive test results. At these STD clinics, provision of posttest counseling varied by HIV serostatus, age, race/ethnicity, test type, and risk category; however, documentation of posttest counseling was missing for more than 20% of tests. The newly identified HIV positivity among all testers was 0.7%.

**Conclusions.** One of the main goals of HIV counseling and testing is to inform people of their HIV status, because knowledge of one's HIV-positive serostatus can result in a reduction in risk behaviors and allow the person to access HIV medical care and treatment. STD clinics offering HIV testing may need to further their emphasis on increasing the proportion of clients who are provided posttest counseling and on improving documentation of this information.

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More than one million people are living with human immunodeficiency virus (HIV) in the United States. The Centers for Disease Control and Prevention (CDC) estimated that in 2006, 56,300 people became newly infected with HIV, which was 40% higher than previous estimates of HIV incidence.[1] HIV counseling and testing (CT) has played a key role in the fight against HIV. Knowledge of HIV serostatus through early detection of HIV infection can allow the person better access to care, medication, counseling, and partner services. It is estimated that increasing the number of people who know their HIV status from 75% to 95% could reduce new HIV infections in the U.S. by almost one-third within one year.[2] A previous study found a surge in safer sex behaviors among people who recently tested for HIV, indicating the benefit of HIV CT regardless of serostatus.[3] People who are aware of their HIV infection can access medical care and antiretroviral therapy, which can improve the quality and length of their lives. Additionally, antiretroviral therapy can reduce the risk for HIV transmission to the infected person's sexual and needle-sharing partners by reducing the viral load in blood and genital secretions.[4–6] CDC recommends routine HIV screening for people aged 13–64 years in health-care settings, including sexually transmitted disease (STD) clinics, where the prevalence of previously undiagnosed HIV is ≥0.1%. These recommendations state that prevention counseling is strongly encouraged for people receiving HIV screening in STD clinics.[7]

STD clinics have historically reported high HIV prevalence rates, ranging from 1% to 18% among clinic clients, 40% of whom did not know their HIV serostatus.[8–11] In the U.S., 23% of all cases of HIV infection detected in public CT sites are detected in STD clinics.[12] Clients of STD clinics tend to be male,[10,13–16] single,[14] African American,[10,14–18] young,[10,14,17] and heterosexual.[10,18] Among clients tested from 1993 to 1997 in STD clinics, 26% of men who have sex with men (MSM) and more than 2% of heterosexuals were HIV-positive.[19]

One of the major goals of HIV CT is to inform people of their HIV serostatus. This CT must include the provision of test results and posttest counseling. We used the HIV Counseling and Testing System (HIV CTS) database to analyze tests conducted in CDC-funded STD clinics to determine characteristics of tests among people not self-reporting a previous HIV-positive diagnosis with provision of test results and posttest counseling. We examined provision of test results and posttest counseling by using one variable, posttest counseling, which is consistent with interpretations of this variable in a previous report.[12] Posttest counseling protocols at this time included the provision of test results and posttest counseling. Hereafter, we will refer to the documentation of provision of test results and posttest counseling as "posttest counseling."

In 1997 and 1998, clients did not receive results from 33% of the HIV tests conducted at CDC-supported CT sites in the U.S.[20] Low return rates impede the main goal of HIV CT—to make individuals aware of their serostatus so that they can access treatment options and make informed choices about future behaviors.[21] Low provision of posttest counseling has been identified as a problem for CDC-funded STD clinics that conduct HIV testing. Fewer than half of the people tested in STD clinics were provided posttest counseling in 1990.[22] To our knowledge, no study has since assessed the provision of posttest counseling among tests conducted in CDC-funded STD clinics. We used the HIV CTS data from 2007, as they afforded the unique opportunity to examine HIV testing data from STD clinics specifically.

## METHODS

### Data source

CDC began funding state and local health departments to provide HIV CT services in 1985.[23] In 1989, CDC developed the HIV CTS to assist national and local monitoring and evaluation of HIV CT services.[24] Information about clients is elicited and documented by a service provider for each HIV test. Data are sent to the appropriate health department and then submitted to CDC.

Although CDC recommended that all health departments collect and report test-level data (i.e., files with data on individual tests), aggregate-level data (i.e., tables of summary counts of information) were accepted in 2007 from 29 of 59 CDC-funded health departments without the sufficient resources or infrastructure to report test-level data to the HIV CTS. Health departments providing aggregate-level data submit a minimal number of variables (e.g., overall number of tests and HIV positivity). All HIV CT data reported to CDC do not include personal identifiers, making it impossible to link any test to a client; therefore, the HIV test data represent tests rather than individuals. CT data are collected to facilitate program monitoring and evaluation at the local, state, and national levels.

### Inclusion criteria

There were five inclusion criteria for this analysis. First, only HIV tests from the 30 health departments reporting test-level data in 2007 were included. Second, only HIV tests reported from the STD clinic site type were included (24 health departments). Third, each test must have had a valid value for the HIV test result

variable (i.e., negative, positive, inconclusive, or no result). Fourth, each test must have been conducted among adolescents and adults aged 13–98 years to mirror the lower age limit of the CDC recommendations and allow for inclusion of older adults seeking HIV testing at STD clinics. Fifth, each test must have been conducted for people who were not previously diagnosed with HIV by self-report.

**Variables analyzed**

Demographic characteristics included gender, age at time of HIV testing, race/ethnicity (i.e., non-Hispanic white, non-Hispanic black, Hispanic, Asian/Pacific Islander, American Indian/Alaska Native, and other), and the state or city in which the HIV test was conducted. These states and cities included California (excluding San Francisco and Los Angeles), Chicago (Illinois), Colorado, Delaware, District of Columbia, Florida, Georgia, Idaho, Kentucky, Louisiana, Massachusetts, Michigan, Missouri, New Jersey, New Mexico, Ohio, Oregon, Pennsylvania (excluding Philadelphia), Rhode Island, San Francisco, South Carolina, Texas (excluding Houston), Utah, and Virginia.

HIV risks were elicited at the time of HIV testing. Transmission mode was categorized hierarchically and based on the presumed likelihood of HIV transmission, as previously described (MSM/injection drug user [IDU], MSM only, IDU only, high-risk heterosexual contact, low-risk heterosexual contact, no acknowledged risk, and other).[24] "Previously tested for HIV" was defined as a record that had documentation of a self-reported previous HIV test and the result. Test type was either anonymous (i.e., no personal identifiers were collected) or confidential (i.e., personal identifiers were collected locally, though not sent to CDC). "Requested an HIV test" was defined as a record that had documentation of requesting an HIV test as the reason for the visit. "Current HIV test result" was dichotomized to positive test results and negative and other test results (i.e., inconclusive and no result). "Newly identified HIV-positive" was defined as a record for which there was a current HIV-positive test but no history of a previous self-reported HIV-positive test. "People not previously diagnosed with HIV" was defined as a record for which there was no self-reported previous HIV-positive test result. "Provision of posttest counseling" referred to whether the record had documentation that test results and posttest counseling were provided to the client specific to the current HIV test. This variable was categorized as yes, no, and missing.

**Analysis**

We used SAS® version 9.2 to calculate and analyze HIV positivity, newly identified HIV positivity, and percentage of tests with documentation of posttest counseling, by demographic and HIV-related characteristics.[25] Some of the 29 health departments excluded from the analysis were in the process of transitioning to a new set of testing variables, which were not equivalent to the HIV CTS variables. Subsequently, 2007 is the most recent year that allows for accurate information about HIV testing conducted in STD clinics. Documentation of the provision of posttest counseling was missing for more than 20% of tests; as such, no regression analyses were conducted.

## RESULTS

As shown in the Table, a total of 372,757 tests from CDC-funded STD clinics in 24 state and local health departments in the U.S. in 2007 were included in the final dataset. In 2007, the highest percentages of tests among people not previously diagnosed with HIV were among males (51.8%), people aged 20–29 years (49.5%), black people (49.6%), those who reported low-risk heterosexual contact (38.9%), people previously tested who were not HIV-positive (57.4%), people testing confidentially (98.2%), and those who did not cite requesting an HIV test as a reason for the visit (62.6%). The newly identified HIV positivity among testers was 0.7%.

In 2007, the percentage of tests with provision of posttest counseling was 51.4% overall, 51.3% among those with HIV-negative test results, and 71.2% among those with newly identified HIV-positive test results. Notably, documentation of provision of posttest counseling was unknown (i.e., missing) for 21.9% of all tests, 22.0% of HIV-negative tests, and 13.3% of newly identified HIV-positive tests. Among newly identified HIV-positive tests, the highest percentage of tests with provision of posttest counseling was among clients who were aged 13–19 years (79.3%), Asian/Pacific Islanders (89.3%), those in the "other" transmission mode category (80.0%), and those who were tested anonymously (81.5%). It should be noted, however, that there were very few individuals in each of these categories, with the exception of people aged 13–19 years. Slight differences were observed by gender, previous test history, and those who requested an HIV test. Among HIV-negative tests, the highest percentage of tests with provision of posttest counseling was among clients who were ≥50 years of age (59.8%), of "other" race/ethnicity (65.3%), in the MSM category (63.1%),

**Table. Provision of HIV test results and posttest counseling as documented on HIV test records at STD clinics among people not previously diagnosed with HIV, by test result, demographics, and HIV test characteristics: 24 health departments, U.S., 2007**

| | | *Provision of test result and posttest counseling*[a] | | | | | |
|---|---|---|---|---|---|---|---|
| | | *Yes* | | *No* | | *Missing* | |
| | *Total tests* | *HIV-negative and other test results*[b] | *Newly identified HIV-positive test results*[c] | *HIV-negative and other test results*[b] | *Newly identified HIV-positive test results*[c] | *HIV-negative and other test results*[b] | *Newly identified HIV-positive test results*[c] |
| *Characteristic* | N *(percent)* | N *(percent)* | N *(percent)* | N *(percent)* | N *(percent)* | N *(percent)* | N *(percent)* |
| Total[d,e] | 372,757 (100.0) | 189,660 (51.3) | 1,922 (71.2) | 99,129 (26.8) | 419 (15.5) | 81,269 (22.0) | 358 (13.3) |
| Gender | | | | | | | |
| Male | 193,118 (51.8) | 102,084 (53.4) | 1,500 (71.4) | 51,139 (26.8) | 321 (15.3) | 37,795 (19.8) | 279 (13.3) |
| Female | 174,621 (46.8) | 86,399 (49.6) | 398 (69.7) | 47,692 (27.4) | 97 (17.0) | 39,959 (23.0) | 76 (13.3) |
| Age group (in years) | | | | | | | |
| 13–19 | 60,017 (16.1) | 28,168 (47.1) | 138 (79.3) | 16,102 (26.9) | 24 (13.8) | 15,573 (26.0) | 12 (6.9) |
| 20–29 | 184,531 (49.5) | 91,332 (49.8) | 772 (71.2) | 51,131 (27.9) | 168 (15.5) | 40,984 (22.3) | 144 (13.3) |
| 30–39 | 67,680 (18.2) | 35,821 (53.5) | 482 (71.5) | 17,686 (26.4) | 105 (15.6) | 13,499 (20.1) | 87 (12.9) |
| 40–49 | 39,699 (10.7) | 22,035 (56.3) | 372 (70.5) | 9,630 (24.6) | 83 (15.7) | 7,506 (19.2) | 73 (13.8) |
| ≥50 | 20,830 (5.6) | 12,304 (59.8) | 158 (66.1) | 4,580 (22.2) | 39 (16.3) | 3,707 (18.0) | 42 (17.6) |
| Race/ethnicity | | | | | | | |
| Non-Hispanic white | 129,427 (34.7) | 68,594 (53.2) | 433 (71.8) | 29,908 (23.2) | 84 (13.9) | 30,322 (23.5) | 86 (14.3) |
| Non-Hispanic black | 185,052 (49.6) | 90,161 (49.2) | 1,166 (68.5) | 54,900 (29.9) | 292 (17.1) | 38,288 (20.9) | 245 (14.4) |
| Hispanic | 43,879 (11.8) | 23,321 (53.5) | 266 (85.0) | 10,928 (25.1) | 30 (9.6) | 9,317 (21.4) | 17 (5.4) |
| Asian/Pacific Islander | 5,003 (1.3) | 3,175 (63.8) | 25 (89.3) | 1,153 (23.2) | –[f] (10.7) | 647 (13.0) | –[f] (0.0) |
| American Indian/ Alaska Native | 777 (0.2) | 374 (48.6) | –[f] (50.0) | 237 (30.8) | –[f] (25.0) | 158 (20.5) | –[f] (25.0) |
| Other | 3,031 (0.8) | 1,967 (65.3) | 12 (70.6) | 843 (28.0) | –[f] (23.5) | 204 (6.8) | –[f] (5.9) |
| Transmission mode | | | | | | | |
| MSM/IDU | 570 (0.2) | 278 (52.3) | 27 (71.1) | 176 (33.1) | –[f] (7.9) | 78 (14.7) | 8 (21.1) |
| MSM | 21,527 (5.8) | 12,883 (63.1) | 831 (74.0) | 4,714 (23.1) | 157 (14.0) | 2,807 (13.8) | 135 (12.0) |
| IDU | 5,695 (1.5) | 2,735 (48.3) | 18 (62.1) | 1,349 (23.8) | –[f] (10.3) | 1,582 (27.9) | 8 (27.6) |
| High-risk heterosexual contact[g] | 108,561 (29.1) | 61,212 (56.6) | 270 (61.2) | 32,793 (30.3) | 106 (24.0) | 14,115 (13.1) | 65 (14.7) |
| Low-risk heterosexual contact[h] | 145,149 (38.9) | 70,484 (48.7) | 401 (76.2) | 42,064 (29.1) | 75 (14.3) | 32,075 (22.2) | 50 (9.5) |
| No acknowledged risk | 61,625 (16.5) | 24,545 (40.1) | 289 (65.4) | 9,725 (15.9) | 68 (15.4) | 26,913 (44.0) | 85 (19.2) |
| Other[i] | 10,295 (2.8) | 4,720 (46.0) | 36 (80.0) | 1,849 (18.0) | –[f] (4.4) | 3,681 (35.9) | 7 (15.6) |

*continued on p. 436*

and tested anonymously (69.7%). Slight differences were observed by gender, previous test history, and those who requested an HIV test (Table).

## DISCUSSION

The first goal of the National HIV/Acquired Immunodeficiency Syndrome (AIDS) Strategy (NHAS) is to reduce the number of people who become infected with HIV.[26] As previously stated, knowledge of one's HIV-positive serostatus can result in a reduction in risk behaviors,[3] and people with HIV infection who are treated with antiretroviral medications may have lower viral loads,[4–6] thereby decreasing their ability to transmit the infection and improving the quality and duration of their life. Therefore, HIV testing and receipt of

**Table (continued). Provision of HIV test results and posttest counseling as documented on HIV test records at STD clinics among people not previously diagnosed with HIV, by test result, demographics, and HIV test characteristics: 24 health departments, U.S., 2007**

| | | *Provision of test result and posttest counseling*[a] | | | | | |
|---|---|---|---|---|---|---|---|
| | | *Yes* | | *No* | | *Missing* | |
| | *Total tests* | *HIV-negative and other test results*[b] | *Newly identified HIV-positive test results*[c] | *HIV-negative and other test results*[b] | *Newly identified HIV-positive test results*[c] | *HIV-negative and other test results*[b] | *Newly identified HIV-positive test results*[c] |
| *Characteristic* | N *(percent)* | N *(percent)* | N *(percent)* | N *(percent)* | N *(percent)* | N *(percent)* | N *(percent)* |
| Previously tested for HIV | | | | | | | |
| No | 106,708 (28.6) | 57,235 (53.9) | 467 (81.8) | 29,025 (27.3) | 60 (10.5) | 19,877 (18.7) | 44 (7.7) |
| Yes, not HIV-positive | 214,040 (57.4) | 116,307 (54.7) | 1,186 (79.5) | 55,829 (26.3) | 197 (13.2) | 40,413 (19.0) | 108 (7.2) |
| Type of test | | | | | | | |
| Anonymous | 5,440 (1.5) | 3,772 (69.7) | 22 (81.5) | 1,525 (28.2) | 5 (18.5) | 116 (2.1) | –[f] (0.0) |
| Confidential | 366,125 (98.2) | 185,384 (51.0) | 1,892 (71.1) | 97,009 (26.7) | 413 (15.5) | 81,070 (22.3) | 357 (13.4) |
| Requested HIV test | | | | | | | |
| No | 233,487 (62.6) | 112,402 (48.5) | 1,335 (71.2) | 67,525 (29.2) | 325 (17.3) | 51,684 (22.3) | 216 (11.5) |
| Yes | 139,270 (37.4) | 77,258 (55.8) | 587 (71.3) | 31,604 (22.8) | 94 (11.4) | 29,585 (21.4) | 142 (17.3) |
| Newly identified HIV-positive[c] | | | | | | | |
| No | 370,058 (99.3) | 189,660 (51.3) | NA | 99,129 (26.8) | NA | 81,269 (22.0) | NA |
| Yes | 2,699 (0.7) | NA | 1,922 (71.2) | NA | 419 (15.5) | NA | 358 (13.3) |

[a]The denominators for each row percentage can be determined by summing the numbers in the "yes," "no," and "missing" columns for the number of HIV-negative and other test results and the number of newly identified HIV-positive test results, respectively.

[b]HIV-negative test is defined as a record for which the current HIV test result is negative, inconclusive, or "no result."

[c]Newly identified HIV-positive test is defined as a record for which there is a current HIV-positive test result and no history of a previous HIV-positive test.

[d]The number of records for each variable may not sum to the total number of records because of missing information. The numbers and percentages of missing data for the selected variables were as follows: gender: 5,018, 1.3%; race/ethnicity: 5,588, 1.5%; transmission mode: 19,335, 5.2%; previously tested for HIV: 52,009, 14.0%; and type of test: 1,192, 0.3%.

[e]During 2007, the following 24 health departments reported test-level data from STD clinics: California, Chicago, Colorado, Delaware, District of Columbia, Florida, Georgia, Idaho, Kentucky, Louisiana, Massachusetts, Michigan, Missouri, New Jersey, New Mexico, Ohio, Oregon, Pennsylvania, Rhode Island, San Francisco, South Carolina, Texas, Utah, and Virginia.

[f]Indicates the cell size was >0 and <5

[g]Person reporting heterosexual contact who also reported any of the following: sex with partner at risk, diagnosis of an STD, exchange of sex for drugs or money, non-injection drug use during sex, and victim of a sexual assault

[h]Person reporting heterosexual contact and no other risk factor

[i]Person reporting other risk factors (i.e., perinatal exposure, hemophilia, receipt of blood transfusion, or health-care exposure)

HIV = human immunodeficiency virus

STD = sexually transmitted disease

MSM = men who have sex with men

IDU = injection drug user

NA = not applicable

test results and subsequent linkage to care are critical components to the strategy's first goal.

The NHAS established a goal for 2015 of increasing from 79% to 90% the percentage of people living with HIV who are aware of their infection. Our analysis assessed the percentage of tests with provision of posttest counseling for tests conducted in CDC-funded STD clinics, which accounted for the largest number of HIV tests conducted and the second largest number of newly identified HIV-positive test results in 2007.[27] Approximately one-half of HIV tests at CDC-funded STD clinics among people not previously diagnosed

with HIV were provided posttest counseling, although this percentage was higher (71%) when the test result was newly identified HIV-positive. This overall percentage is consistent with previous findings of provision of test results;[20] however, it is much lower than the estimate provided by Holtgrave and Pinkerton that suggests new infections could be reduced by one-third if 95% of people tested in all settings received their HIV test results.[28]

Provision of posttest counseling was higher among newly identified HIV-positive young people compared with newly identified HIV-positive people of all other ages, and among people who were tested anonymously (regardless of test results) compared with people who were tested confidentially. This finding may suggest that STD clinics recognize the difficulty in accessing these populations and have worked harder to retain these clients during the confirmatory test waiting period. A 2002 study by Tsu and colleagues found that returning results via telephone resulted in higher return rates among homeless adolescents, a population that may be especially difficult to reach.[29] In a study assessing anonymous and confidential testing, counselors commonly urge clients to test confidentially because it gives staff members the means to contact clients regarding test results and linkage to care.[30] Furthermore, Grusky and colleagues found that some counselors tried to convert anonymous, HIV-positive clients to confidential testing if they had a preliminary HIV-positive rapid test. When clients refused to be converted, several respondents explained that they used various unofficial means to keep in touch with the clients.[31] The higher percentage of tests with provision of posttest counseling among Asian/Pacific Islanders (regardless of test results) was surprising, given that some reports show a reluctance among this group to seek medical care[32] and delayed entry to care upon HIV diagnosis.[33]

Among people with HIV-negative test results, MSM and older adults (≥50 years of age) were also more likely to have provision of posttest counseling, although STD clinics generally serve younger,[10,14,17] heterosexual[10,18] populations. MSM have been highly impacted by HIV infection since the beginning of the epidemic and may therefore be more aware of the need to know one's serostatus. In addition, national HIV testing guidelines encourage annual screening for MSM,[7] which may impact provision of test results. Older adults may also have had more exposure to these messages over time and may be more focused on their health than young people. In a study comparing health-promoting behaviors, older adults had higher scores in overall health-promoting lifestyle and in the dimensions of health responsibility than both young and middle-aged adults.[34] It is difficult to assess the increased/decreased provision of posttest counseling among people reporting other transmission risks and other race, as the pooling of disparate but less frequently reported risk factors or racial/ethnic groups may mask the unique characteristic that serves as a predictor for these results.

It is also important to note, however, that documentation of posttest counseling was missing for more than 20% of the tests. This figure is similar to the proportion of HIV tests with missing information for documentation of posttest counseling in previous years.[12,24] Monitoring and evaluation of HIV testing programs, in any setting, necessitate the documentation of receipt of all test results, and receipt of posttest counseling among people with HIV-positive test results. It may be postulated that the high percentage of tests with missing documentation of posttest counseling stems from the time frame within which test results and posttest counseling are documented. For example, when test results are provided on the same day as the test, as is possible with rapid test technology, the results may be easily documented on an HIV test form or client chart. However, if there is a delay, there may be an increased likelihood that the documentation of test results and posttest counseling may not be properly conducted. The introduction of rapid HIV testing since 2002 should have increased the documentation of posttest counseling,[35] which was not observed in these results. However, information on use of a rapid HIV test was not reported to CDC in 2007.

It is possible that the increased use of rapid HIV tests had not sufficiently increased by 2007 at STD clinics to achieve improved documentation. STD clinics offering HIV testing may need to increase their emphasis not only on increasing the proportion of clients who are provided test results and posttest counseling, but also on improving the quality assurance of the documentation of this information, as the proportion may be greater than is indicated in this analysis. It should be noted that CDC requires the collection of HIV testing variables and may need to consider evaluating the validity and reliability of these data. CDC does not require that specific data-collection tools or systems be used, but it does encourage evaluation of these tools and systems at the local level. Provision and documentation of posttest counseling may be improved with increased staff training and structural interventions, such as integrating alternate methods of providing test results and posttest counseling. Hutchinson and colleagues found that rapid testing, provision of results by telephone, and home-collection specimen kits significantly increased the provision of test results compared with

conventional HIV testing.[36] Use of other digital media, such as the Internet or text messages, may also prove useful in providing test results and counseling messages in a secure format that users, especially young people, may be accustomed to using.[37–39]

### Limitations

This analysis was subject to several limitations. The testing data presented are not representative of all HIV tests conducted nationally, or even of all HIV testing conducted at CDC-funded STD clinics, as the analysis was limited to those health departments funded by CDC that provided test-level data. Secondly, documentation of posttest counseling was missing for more than 20% of the tests, thereby limiting our ability to conduct statistical analyses. This large proportion of missing data points to the need to increase the percentage of clients who receive test results and posttest counseling, as well as the need to improve program documentation practices. Lastly, provision of test results and posttest counseling used the proxy variable "receipt of posttest counseling." Although posttest counseling protocol includes the provision of test results to clients, it is recommended that the specific provision of results are documented separately from posttest counseling, to lend assurance that these results were in fact provided.

## CONCLUSIONS

The NHAS acknowledges that it will take more than one approach to HIV prevention to bring an end to the epidemic.[26] Multiple approaches should be taken to improve the provision and documentation of HIV test results and posttest counseling. STD clinics should consider offering rapid HIV tests and pairing them with reminders to obtain test results via cell phones, texts, or Internet-based programs in ways that are simple and secure to increase the provision and documentation of HIV test results and posttest counseling. HIV testing programs should assess their quality assurance plans to ensure that the provision of HIV test results takes place and that this activity is documented.

The authors thank Lyle McCormick for his contributions to early analyses of these data. Human immunodeficiency virus testing is a public health program activity, which is not considered by the Centers for Disease Control and Prevention (CDC) to be research; therefore, it did not require Institutional Review Board approval.

The findings and conclusions in this article are those of the authors and do not necessarily represent the views of CDC.

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# Environmental Health

This article by Licudine et al. represents another important concept in epidemiology: exposure assessment. Environmental assessment is a relatively new concept; the first time it was formally addressed by the Environmental Protection Agency (EPA) was in the mid-1980s. In fact, exposure assessment represents the predominant part of EPA risk assessments. The revised EPA Guidelines for Exposure Assessment carefully address several key concepts, including measurement of exposure, intake, uptake, and dose. Each of these concepts is essential to the understanding of health effects related to environmental exposures.

The authors explore the seemingly innocuous activity of observing New Year fireworks displays. The authors measured exposure and documented the presence of several contaminants in ambient air during the New Year celebrations. These contaminants may pose long-term exposure risk and may be associated with adverse health effects. Hopefully, future investigators will take the next steps and evaluate potential longer-term environmental and health impacts by implementing the other concepts involved in exposure assessment: intake, uptake, and dose.

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## HAZARDOUS METALS IN AMBIENT AIR DUE TO NEW YEAR FIREWORKS DURING 2004–2011 CELEBRATIONS IN PEARL CITY, HAWAII

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Honolulu, Hawaii, has consistently recorded the cleanest air among large U.S. cities, except once a year during New Year celebrations, because of traditional fireworks displays statewide.[1,2] These fireworks result in increased levels of suspended particulates in residential air as high as 300% above the pre-fireworks level, and can cause adverse health effects.[3,4] In recent years, residential fireworks celebrations in Hawaii have become increasingly intense, resulting in more fires and increased human injuries despite laws enacted to curb their use.[5–7] Moreover, dangerous aerial fireworks from illegal importation and sales punctuate the problem, and may lead to even more health and safety hazards because they are unregulated and generate contaminants of largely unknown composition and toxicity.[8,9] Recent legislation has further banned fireworks on the island of Oahu after the 2011 New Year (2011NY) celebration because of health and safety concerns.[10]

Advanced technologies have transformed fireworks propellants, and new oxidizers and color producers enhance visual effects.[11,12] Chlorine-based oxidizers such as chlorates or perchlorates can be used to achieve noise levels equivalent to trinitrotoluene and result in more violent explosions than traditional nitrates.[13] Demand for fireworks with designer colors has resulted in increased use of metals as color producers.[14,15] Lead (Pb) salts are widely used as igniters to initiate fireworks explosions.[16] Manganese (Mn) and Mn dioxide serve as fuel and oxidizer for brighter lights,[17] chromium (Cr) is used as a burn rate catalyst for propellants,[18] and nickel (Ni) acts as an electric firing device for fireworks.[19]

Concern regarding environmental and health risks has developed because metals are generally persistent in the environment, perchlorates have been associated with thyroid problems,[20] and toxic byproducts (e.g., dioxins) could be produced as a result of atmospheric reactions between metal oxides and organic fuels.[21] Before and after every New Year celebration, the Hawaii State Department of Health (HDOH) issues health advisories to the public and reports the amount of particulate matter (PM), specifically the $PM_{10}$ (≤10 microns [μm]) dispersed in the air during the festivities. The 2005NY celebration resulted in $PM_{10}$ levels that exceeded the state and federal 24-hour $PM_{10}$ standard of 150 micrograms per cubic meter [$\mu g/m^3$].[22] Short-term exposure to very high levels of PM during fireworks episodes have caused asthma problems and other respiratory ailments in Hawaii[3,4,23] and elsewhere.[24,25] Furthermore, short- and long-term exposures to the smaller particulates $PM_{2.5}$ (≤2.5 μm) have been associated with increased cardiovascular and lung cancer mortality.[26,27]

In 1975, the presence of potassium chloride and

sulfur dioxide in Oahu ambient air during the New Year fireworks celebration was documented by Smith and Dinh in connection with a health-related study.[23] In recent years, significant increases in ambient air barium (Ba), strontium (Sr), magnesium (Mg), Pb, Mn, and other metals have been reported during fireworks-related festivities in Spain,[28] China,[29] India,[30] and Italy.[31] To document the concentrations of metals in central Oahu ambient air during New Year fireworks celebrations, we sought additional air sampling from 2004NY–2011NY, following the U.S. Environmental Protection Agency (EPA) Air Toxics program methodology. In the Air Toxics program, the six core metals—Pb, Mn, Cr, Ni, cadmium (Cd), and beryllium (Be)—are monitored, arsenic (As) and mercury (Hg) are excluded from the inorganic hazardous air pollutant (HAP) list, and Pb is the only metal regulated.[32,33] The EPA began an assessment of cancer and non-cancer health risks associated with exposure to various toxic chemicals in 1999, and adverse health effects of HAP metals that were published in 2005[34] are summarized in Table 1. Additional toxicity associations[35,36] and cancer tissue metal accumulations[37,38] have been described in workers with well-characterized exposure to metal-rich particles. Excessive exposure to some heavy metals may have led to mental dysfunction and neurological disorders.[39,40] Recent findings associated exposure to Pb, Mn, and other metals with the development of neurodegenerative disorders mimicking Parkinson's, Alzheimer's, and Huntington's diseases.[41,42]

Although some of these HAP metals have desirable characteristics in pyrotechnics, other materials should be used to avoid known toxicities. The American Fireworks Standards Laboratory (AFSL) has prohibited the use of Pb, As, and Hg salts in the manufacture of fireworks.[43] In this article, we document the presence of contaminants in ambient air collected over the HAP pilot site of Pearl City in central Oahu during 2004NY–2011NY celebrations.

## METHODS

### Air sampling

The metal sample collection was conducted in Pearl City on central Oahu because routine monitoring indicated historically high ambient particulates during New Year fireworks celebrations, as compared with other sites on the island of Oahu.[22] Air sampling for

**Table 1. Toxicological evaluation of EPA hazardous air pollutant metals, health risks, and benchmarks**

| *Metals* | *Health risk*[a,b] *(cancer/non-cancer)* | *EPA benchmark*[c] *(ng/m³)* |
|---|---|---|
| 1. Arsenic | Respiratory cancer/developmental | 0.57 |
| 2. Beryllium | Lung cancer/respiratory | 1.00 |
| 3. Cadmium | Lung cancer/kidney | 1.40 |
| 4. Chromium[d] | Lung cancer/respiratory | 0.20,[e] 0.01[f] |
| 5. Lead | None/developmental | 1,500.00,[g] 150.00[h] |
| 6. Manganese | None/neurological | 52.00[i] |
| 7. Mercury | None/neurological | 310.00,[j] 31.00[k] |
| 8. Nickel | Lung cancer/immunological | 10.00 |

[a]Environmental Protection Agency (US), National-Scale Air Toxics Assessment Program. Health effects information used in cancer and noncancer risk characterization for the 1999 national-scale assessment [cited 2010 Dec 10]. Available from: URL: http://www.epa.gov/ttn/atw/nata1999/tables.html

[b]Agency for Toxic Substances and Disease Registry (US). ToxFAQS™ for HAP metals [cited 2011 Apr 11]. Available from: URL: http://www.atsdr.cdc.gov/toxfaqs/index.asp#bookmark04

[c]EPA benchmark for resident air based on minimum concentration for carcinogenic target risk or non-cancer hazard index (i.e., lead, manganese, and mercury) on lifetime exposure as of November 2011

[d]Total chromium (Cr) (1:6 ratio Cr VI:Cr III)

[e]Carcinogenic target risk based on total Cr before November 2010

[f]Carcinogenic target risk based on hexavalent Cr ($Cr^{+6}$) starting with the November 2010 update

[g]National ambient air quality standard for lead before October 15, 2008

[h]New national ambient air quality standard for lead starting October 15, 2008

[i]Non-cancer hazard index for manganese

[j]Elemental mercury non-cancer hazard index

[k]Non-cancer hazard index for mercury salts as of November 2011

EPA = Environmental Protection Agency

ng/m³ = nanograms per cubic meter

metals was performed using two Graseby Andersen high-volume samplers (Andersen Instruments Inc., Smyrna, Georgia) capable of maintaining a flow rate of ~1.0 $m^3$/minute for 24 hours following EPA protocols.[44] The total suspended particulates (TSP) samples as defined by the EPA[45] were collected in 8-by-10-inch spectro-quality-grade glass fiber filters provided by the EPA. New Year's Eve sampling spanned 24 hours, starting at 12 a.m. on December 31 and ending at 11:59 p.m. on December 31 (Table 2). New Year's Day sampling also spanned 24 hours, starting at 12 a.m. on January 1 and finishing at 11:59 p.m.

The EPA has an official sampling schedule each year, and it included New Year's Day 2008 and 2009. EPA sampling dates that occurred closest before and after New Year's Day represented pre-fireworks and post-fireworks sampling, respectively. If New Year's Eve or New Year's Day sampling did not coincide with the EPA's official sampling date (years other than 2008 and 2009), special sampling for that day was conducted, except for 2006NY. For 2006NY, the official EPA sampling schedule interfered with the ability to sample 2006 New Year's Eve. Specifically, the EPA sampling ended on Friday, December 30, 2005, at midnight, and no technicians were available to set up the sampler during the weekend for New Year's Day sampling, so those data were not collected. The $PM_{10}$ data were generated from a BAM-1020 $PM_{10}$ continuous sampler (Met One Instruments, Inc., Grants Pass, Oregon) that measures particulates hourly. The meteorological data (wind speed and precipitation) based on Honolulu international airport weather station reports were downloaded from http://www.wunderground.com (Table 2).

**Sample preparation and analysis**

A 1¾-by-2¼-inch portion of the TSP filter was extracted with 40 milliliters of 0.25 normal (N) nitric acid ($HNO_3$) solution using the Bransonic® 8510 Ultrasonic Cleaner (Branson Ultrasonics, Danbury, Connecticut) set at 60° C for about two hours. The acid extract was filtered through a 0.45 µm nylon filter using a Pall Gelman magnetic filter funnel (Pall Life Sciences Inc., Ann Arbor, Michigan). Blank filters and quality control samples were also prepared and extracted following our standard laboratory procedure, which was audited and approved by the EPA in 2008.[46] The 2004NY and 2005NY fireworks samples were re-extracted and analyzed following the EPA approved methodology.

**Table 2. Meteorological conditions during fireworks: New Year celebrations in Pearl City, Hawaii, 2004NY–2005NY and 2007NY–2011NY**

| *Year*[a] | *Sampling date (24 hours)* | *Fireworks event (date/time)*[b] | *Average wind speed (miles per hour)* | *Precipitation (inches)* |
|---|---|---|---|---|
| 2004NY | 12/31/2003 (12 a.m.–11:59 p.m.) | 12/31/2003 (5:53 p.m.–11:53 p.m.) | 5.5 | 0.03 |
| 2005NY | 12/31/2004 (12 a.m.–11:59 p.m.) | 12/31/2004 (5:53 p.m.–11:53 p.m.) | 6.9 | 0.00 |
| 2007NY | 12/31/2006 (12 a.m.–11:59 p.m.) | 12/31/2006 (5:53 p.m.–11:53 p.m.) | 9.1 | NA |
| 2008NY | 1/1/2008 (12 a.m.–11:59 p.m.) | 1/1/2008 (12:53 a.m.–5:53 a.m.) | 8.3 | NA |
| 2009NY | 1/1/2009 (12 a.m.–11:59 p.m.) | 1/1/2009 (12:53 a.m.–5:53 a.m.) | 8.6 | 0.44 |
| 2010NY | 1/1/2010 (12 a.m.–11:59 p.m.) | 1/1/2010 (12:53 a.m.–5:53 a.m.) | 4.6 | NA |
| 2011NY | 12/31/2010 (12 a.m.–11:59 p.m.) | 12/31/2010 (5:53 p.m.–11:53 p.m.) | 4.5 | NA |

[a]New Year fireworks event, except 2006NY (sampling not conducted)

[b]Actual meteorological data computed for the specified date and time

NY = New Year

NA = not available

**Table 3. Method comparative analysis for hazardous air pollutant metals during 2005 New Year celebrations in Pearl City, Hawaii**

| | *Method quantitation limit* | | | *Quantitative analysis comparison*[a] | | |
|---|---|---|---|---|---|---|
| *HAP metals* | *Mass (amu)* | *GFAAS (ng/m³)* | *ICP-MS (ng/m³)* | *GFAAS (ng/m³)* | *ICP-MS (ng/m³)* | *RPD (percent)* |
| 1. Beryllium | 9 | 0.20 | 0.20 | <MQL | <MQL | NA |
| 2. Cadmium | 111 | 0.08 | 0.10 | 1.4 | 1.6 | 13.3 |
| 3. Chromium | 52 | 0.79 | 0.29 | 144.7 | 157.6 | 8.5 |
| 4. Lead | 208 | 0.98 | 0.29 | 307.0 | 253.0 | 19.0 |
| 5. Manganese | 55 | 0.79 | 0.71 | 100.3 | 87.8 | 13.3 |
| 6. Nickel | 60 | 1.18 | 0.10 | 5.3 | 6.0 | 12.4 |

[a]2005 New Year sample collected from the main site in Pearl City, Hawaii, with concentration in ng/m³

HAP = hazardous air pollutant

GFAAS = graphite furnace atomic absorption spectroscopy

ICP-MS = inductively coupled plasma mass spectrometry

RPD = relative percent deviation

amu = atomic mass unit (of the metal isotope)

ng/m³ = nanograms per cubic meter

MQL = method quantitation limit (based on the lowest calibration standard)

NA = not applicable

We analyzed ambient air samples during 2004NY–2011NY celebrations by graphite furnace atomic absorption spectroscopy (GFAAS) using a PerkinElmer 4110ZL AA instrument with transversally heated graphite atomizer and AS-72 autosampler (PerkinElmer Corporation, Waltham, Massachusetts). Initial confirmation and comparison analysis of HAP metals was performed by inductively coupled plasma-mass spectrometry (ICP-MS) using a PerkinElmer ELAN DRC II ICP-MS (PerkinElmer) (Table 3). The ICP-MS methodology was also used to further analyze 2005NY and 2008NY samples, including pre-fireworks and post-fireworks ambient air samples, to determine peaks and dissipation of HAPs and other metals.[47]

### Data analysis

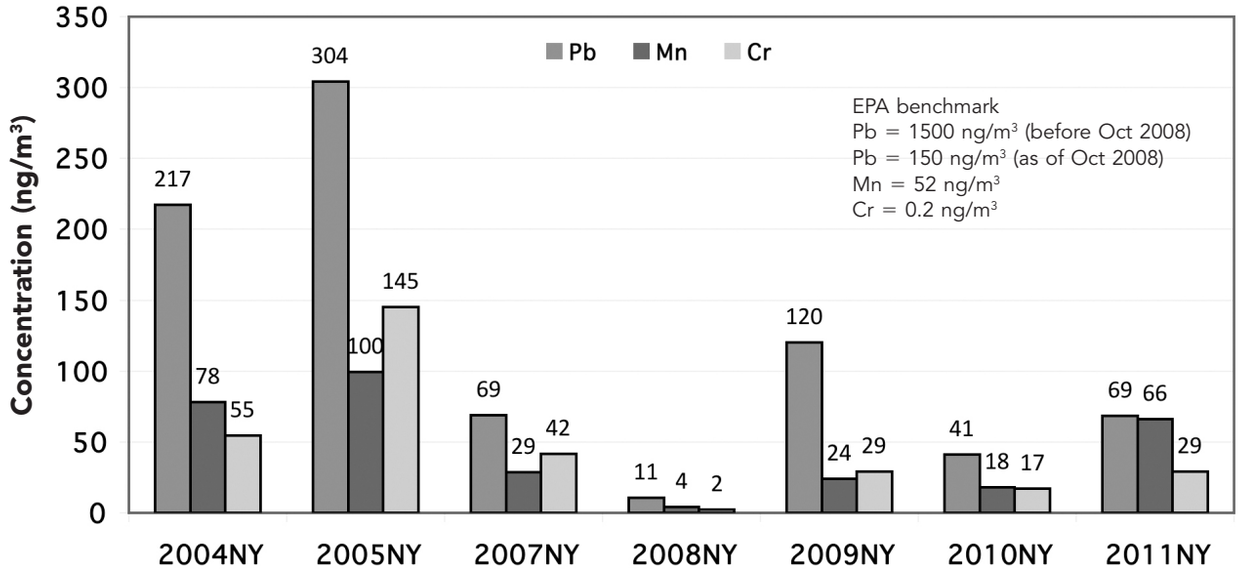
Mass data obtained from GFAAS and ICP-MS were corrected for filter blanks and then divided by the collected sampling volume to determine concentration of metal analytes in ambient air. We used the Pb-to-TSP ratio as an indicator of illegal fireworks activity and computed it as the quotient of ambient concentrations of Pb and TSP multiplied by 100. We compared the ambient air metal concentrations during fireworks displays with those before firework activity to determine peak and measured the dissipation as the time necessary for metal concentrations to return to pre-firework levels. We computed the residence time ($\tau$) of $PM_{10}$ particulates by dividing the highest concentration of the particulates by the rate of removal in the atmosphere.[48] Quality management chemists from the Environmental Health and Analytical Services Branch of HDOH reviewed and assured data quality.

## RESULTS

### Detection of HAP metals during 2004NY–2011NY celebrations

During 2004NY and 2005NY celebrations (Figure 1a), Pb peaks were highest at 217 ng/m³ and 304 ng/m³, respectively, but these values were lower than the National Ambient Air Quality Standard of 1,500 ng/m³ during that time. Levels of Cr at 55 ng/m³ in 2004NY peaked even higher at 145 ng/m³ in 2005NY. These values were 275 and 725 times the EPA benchmark of 0.2 ng/m³ for Cr, respectively. Concentrations of Mn peaked at 78 ng/m³ in 2004NY and 100 ng/m³ in 2005NY, both of which exceeded the EPA benchmark of 52 ng/m³. From 2007 to 2011, Pb, Mn, and Cr concentrations decreased dramatically and, with the exception of Cr, were below EPA benchmarks. Cadmium concentrations exceeded the benchmark value of 1.4 ng/m³ in 2007NY (1.9 ng/m³) and reached benchmark in 2005NY (1.4 ng/m³) (Figure 1b). Interestingly, Cd was detected below the benchmark level in 2004NY (1.1 ng/m³), 2009NY (0.8 ng/m³), 2010NY (0.6 ng/m³), and 2011NY (0.4 ng/m³), and below the method quantitation limit (MQL) in 2008NY. Peak Ni concentration was highest during 2005NY (8.2 ng/m³); however, none of the samples exceeded the EPA benchmark for Ni at 10 ng/m³. Beryllium was not found in any ambient air samples at the analytical limit of detection.

**Figure 1a. Ambient air concentrations of Pb, Mn, and Cr during 2004NY–2005NY and 2007–2011NY fireworks celebrations in Pearl City, Hawaii**




Pb = lead
Mn = manganese
Cr = chromium
NY = New Year
EPA = Environmental Protection Agency
ng/m³ = nanograms per cubic meter

**Detection of HAP metal peak concentrations during 2005NY and 2008NY celebrations**

The presence of the HAP metals was determined by ICP-MS based on their isotopic masses, as shown in Table 3. Comparison of the quantitative analysis of the HAP metals by GFAAS and ICP-MS from a 2005NY ambient air sample demonstrated a relative percent deviation of ≤19% for all metals. Although either method would have been acceptable in the analysis of the six HAP metals in this study, we chose ICP-MS because of its lower quantitation limits for most HAP metals (Table 3) and the convenience of analyzing multiple metals in a single analysis. Consequently, we used ICP-MS to determine peaks and dissipation of HAP metals including As, Hg, and other fireworks-related metals.

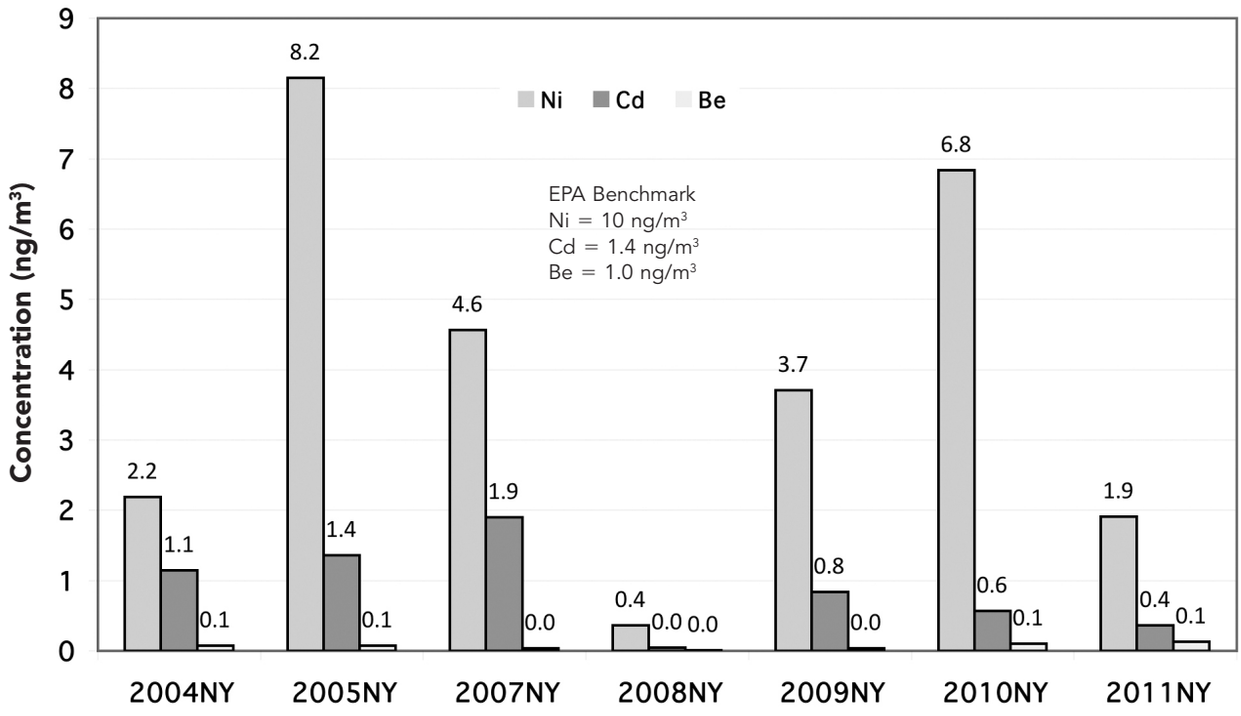
In 2005NY, HAP metal Pb increased 158-fold, and Cd, Mn, Cr, and Ni (Table 4) also increased substantially compared with pre-fireworks levels. Arsenic at 7.6 ng/m³ was just higher than the MQL of 6.4 ng/m³, while Hg and Be were below the MQL and not listed in Table 4. In 2008NY, much lower concentrations of HAP metals Pb (11 ng/m³), Cr (2 ng/m³), and Mn (4 ng/m³) were measured on New Year's Day. Pb levels were five times the pre-fireworks concentrations, while all other HAP metals had lower peaks (data not shown).

**Pb-to-TSP ratio compared with fireworks consumption during 2004NY–2011NY celebrations**

During regular monitoring, the Pb-to-TSP ratio ranged from 0.01% to 0.03%. After New Year's celebrations, the ratio increased above 0.04% and often rose much higher (Figure 2a; 2006NY data not available). Ratios occasionally increased after July 4 celebrations, but only reached the 0.04% level in 2003 and 2008. Very high Pb-to-TSP ratios were observed during the last three years (2009NY–2011NY), the highest ratio being in 2009NY (0.12%).

Fireworks importation has generally increased since 2004NY (Figure 2b),[5] although permits issued began declining in 2006NY. Starting with 2010NY, fireworks import measurements changed from cases to pounds and, thus, were no longer comparable with previous years' data. The 2011NY was the last year residential fireworks were to be allowed in Hawaii, and fireworks permit sales rose to 10,008 permits, which was a 24%

**Figure 1b. Ambient air concentrations of Ni, Cd, and Be during 2004NY–2005NY and 2007–2011NY fireworks celebrations in Pearl City, Hawaii**




Ni = nickel
Cd = cadmium
Be = beryllium
NY = New Year
EPA = Environmental Protection Agency
ng/m³ = nanograms per cubic meter

increase from the previous year of 8,055 permits. Although the highest total volume of fireworks imports was recorded in 2007NY, a lower Pb-to-TSP ratio of 0.06% was observed for that year.

**Elevation of other metals in ambient air during the 2005NY and 2008NY celebrations**

During the 2005NY celebration, extremely high concentrations of Sr, potassium (K), copper (Cu), aluminum (Al), Mg, and sodium (Na), and moderately high concentrations of bismuth (Bi), antimony (Sb), zinc (Zn), Ba, titanium (Ti), and iron (Fe) were found (Table 4). Three days before the 2005NY celebration (on December 29, 2004), high concentrations of known fireworks-related metals (e.g., Mg, Al, K, and Ba) were already detected in ambient air, most likely due to sporadic fireworks use in the days leading up to New Year's Day. After midnight on New Year's Eve, ambient air concentrations of Bi, Sr, K, Sb, Cu, Zn, Al, Mg, rubidium (Rb), and Ba increased dramatically compared with sampling three days earlier. Although measurement for Na was also high during New Year's Eve and could be attributed to fireworks, we could not rule out the effects of sea salt in the marine atmosphere.[49,50]

In 2008NY, metals that increased substantially compared with pre-fireworks concentrations included Ba (20-fold); selenium (sevenfold); Ag (sixfold); Sr and Ti (fourfold); Rb (threefold); and Bi, Cu, and K (twofold).

**Dissipation of $PM_{10}$ particulates, HAPs, and other metals during 2005NY and 2008NY**

The $PM_{10}$ particulate samples were collected hourly and used as an indicator of the dissipation rate of the fireworks-associated particulates in ambient air (Figure 3). In 2005NY, the particulates began increasing at about 8 p.m. on December 31, peaked around 1:30 a.m. on

January 1, and returned to pre-fireworks levels at about 5:30 a.m. on January 1. The atmospheric residence time ($\tau$)[48] of the $PM_{10}$ particulates was calculated to about four hours, which was fast considering the quantity of particulates. During 2008NY, particulate concentration fluctuated inconsistently, possibly due to stronger trade winds (Figure 3). The 2008NY particulates peaked at about 1:30 a.m. at 0.4 mg/m$^3$, but dropped rapidly to the pre-fireworks level, resulting in an atmospheric residence time of about an hour.

The three-day post-fireworks concentrations of all metals, including HAP, had dissipated to pre-fireworks levels (Table 4) with the exception of Na and Cu, suggesting longer residence time for these metals. However, high Na values measured for three days before and after the event suggested that the high background concentration of Na in Oahu's ambient air was most likely due to atmospheric sea salt from the Pacific Ocean, as reported in other studies.[49,50] Likewise, high background levels of ambient Cu, Al, Mg, and Fe may be explained by the transport of aerosols generated by the long sustained eruption of Hawaii's Kilauea volcano.[51]

## DISCUSSION

This study revealed that HAP metals Pb, Cr, Mn, Cd, Ni, and As, as well as other metals (e.g., Bi, Sr, K, Cu,

**Table 4. ICP-MS analysis of HAPs and screening of other metals detected in Pearl City, Hawaii, ambient air before, during, and after the 2005NY fireworks celebration**

| *Metals* | *Pre-FW (ng/m$^3$)* | *During FW (ng/m$^3$)* | *Post-FW (ng/m$^3$)* | *Peak[a] fold increase* |
|---|---|---|---|---|
| HAP metals[b] | | | | |
| Lead | 1.6 | 253.0 | 1.0 | 158 |
| Cadmium[c] | 0.1 | 1.6 | <MQL | 16 |
| Manganese[c] | 6.0 | 88.0 | 6.0 | 15 |
| Chromium | 11.0 | 158.0 | 9.0 | 14 |
| Nickel[c] | 1.2 | 6.0 | 1.0 | 5 |
| Arsenic | <MQL | 7.6 | <MQL | 1[d] |
| Other metals[e] | | | | |
| Bismuth | 1 | 512 | 0[f] | 512 |
| Strontium | 8 | 1,719 | 6 | 215 |
| Potassium | 647 | 61,016 | 24 | 94 |
| Antimony | 1 | 86 | 0[f] | 86 |
| Copper | 137 | 6,697 | 200 | 49 |
| Zinc[c] | 32 | 581 | 22 | 18 |
| Aluminum | 797 | 7,295 | 212 | 9 |
| Magnesium | 2,040 | 18,409 | 1,299 | 9 |
| Rubidium[c] | 1 | 9 | 0[f] | 9 |
| Barium | 72 | 504 | 0[f] | 7 |
| Silver[c] | 1 | 6 | 0[f] | 6 |
| Titanium | 19 | 57 | 15 | 3 |
| Zirconium | 6 | 12 | 0[f] | 2 |
| Iron | 285 | 606 | 269 | 2 |
| Sodium | 16,767 | 21,743 | 19,450 | 1 |

[a]Peak was the fold increase of metals during fireworks vs. pre-fireworks concentration.

[b]Excluding beryllium and mercury

[c]Metals found in fireworks samples that are neither listed as permitted nor prohibited chemicals for consumer fireworks by American Fireworks Standards Laboratory

[d]Fold increase computed as 2005NY during FW/MQL (6.4 ng/m$^3$)

[e]Other metals analyzed semi-quantitatively by ICP-MS

[f]0 value means that metal in blank filter is higher than exposed filter sample.

IC-PMS = inductively coupled plasma mass spectrometry

HAP = hazardous air pollutant

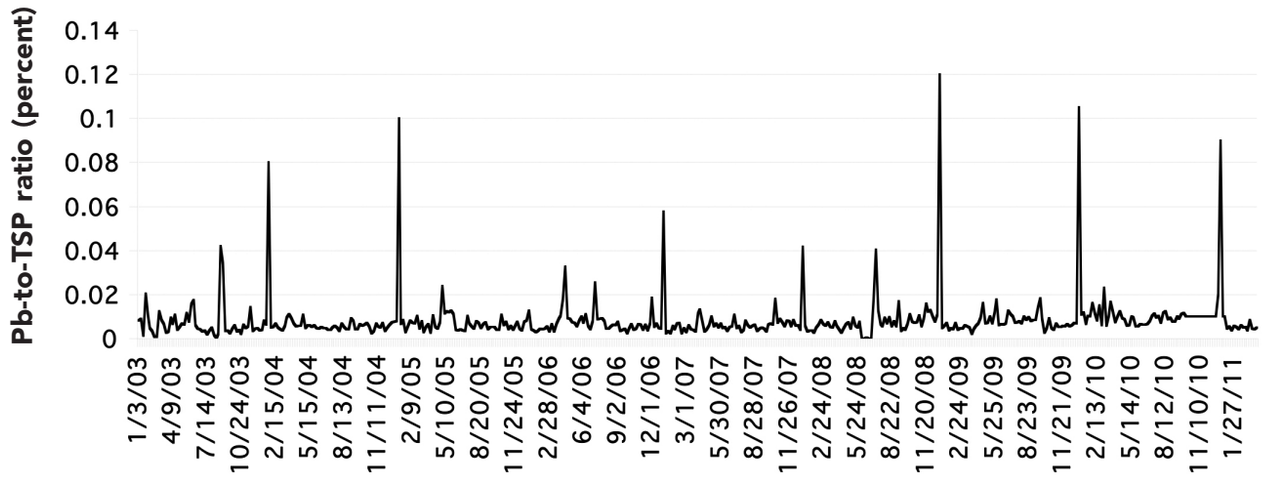
NY = New Year

FW = fireworks

ng/m$^3$ = nanograms per cubic meter

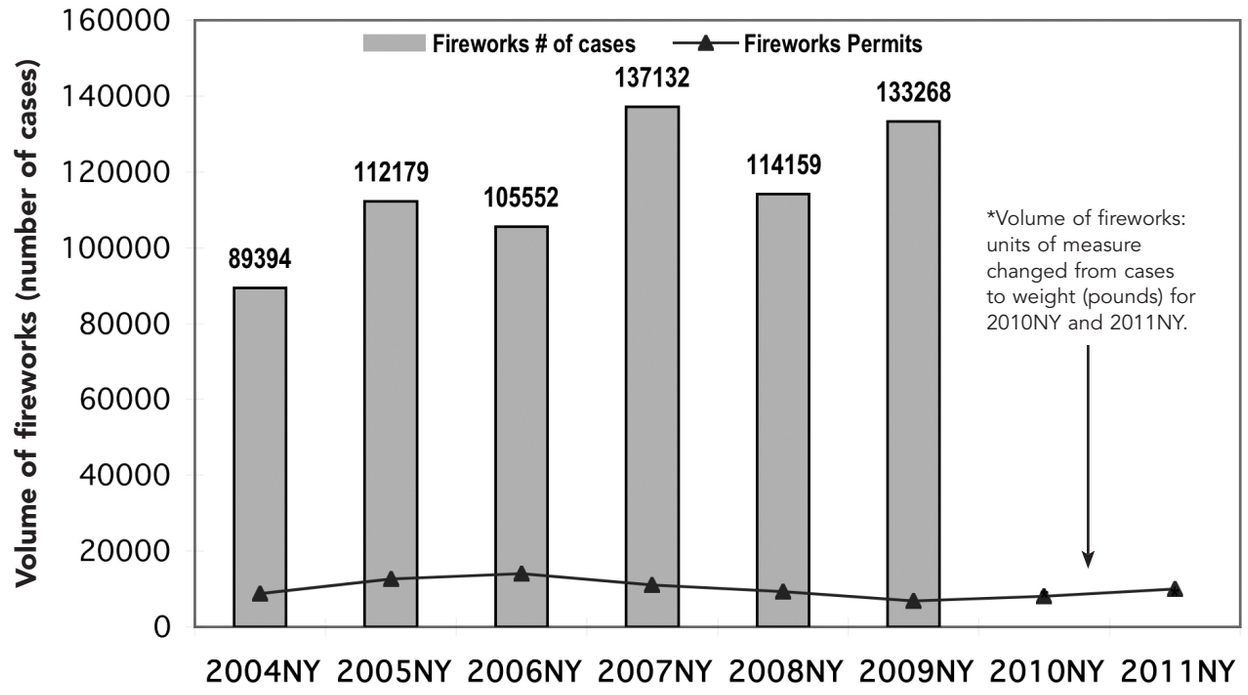
MQL = method quantitation limit

**Figure 2a. Trends of Pb-to-TSP ratio for fireworks particulates collected in Pearl City, Hawaii, during 2004NY–2011NY celebrations**



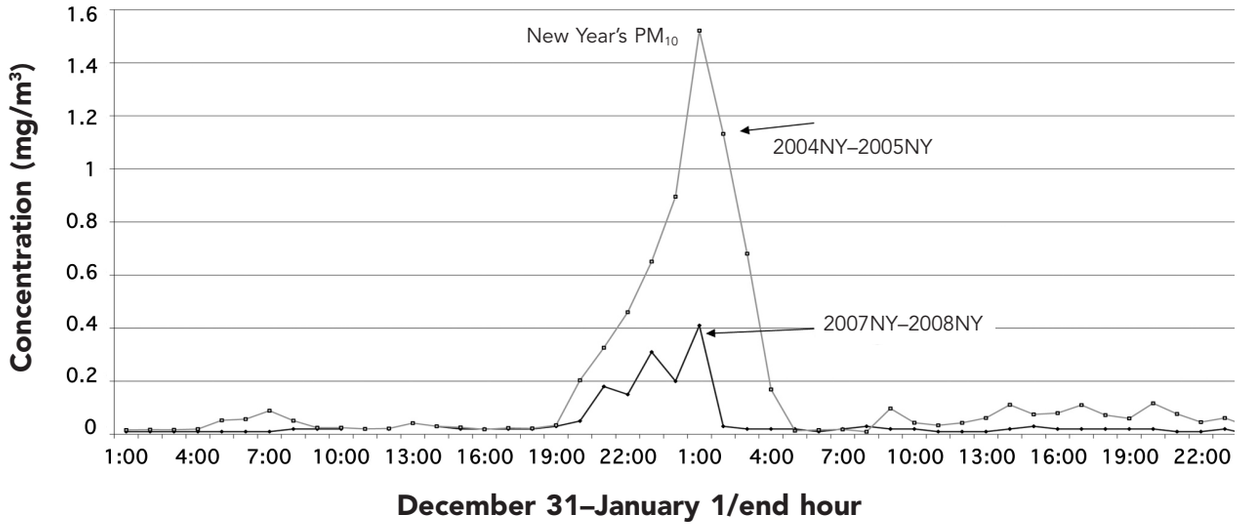

Pb = lead
TSP = total suspended particulates
NY = New Year

**Figure 2b. Fireworks imports and permits issued for 2004NY–2011NY celebrations in Honolulu, Hawaii**




Source: Honolulu Fire Department
NY = New Year

**Figure 3. Accumulation and dissipation of $PM_{10}$ particulates on 2005NY and 2008NY fireworks celebrations in Pearl City, Hawaii**




$PM_{10}$ = particulate matter 10
NY = New Year
$mg/m^3$ = milligrams per cubic meter

Zn, Mg, and Ba), reached high concentrations relative to pre-fireworks ambient air levels and then dissipated quickly. Among the HAP metals, only Pb is regulated by the EPA. In 2008, the three-month standard was revised downward from 1,500 $ng/m^3$ to 150 $ng/m^3$. If the present 150 $ng/m^3$ standard had been in force during the 2004 and 2005 celebrations, Hawaii would have briefly (24-hour level vs. the three-month EPA standard) exceeded the Pb levels. Cd and As were also found, but the low concentrations indicate that these might just have been impurities in other metals such as Pb, Cu, or Zn.[52,53] Cr was analyzed as total Cr; however, based on the 2010 update of the Risk-Based Concentration (RBC) table,[54] the EPA benchmark was no longer listed for total Cr but only for the more toxic hexavalent Cr species ($Cr^{+6}$), which was not analyzed in this study. Surprisingly, Cr as dichromate, a potential source of hexavalent Cr, is allowed by AFSL, although not exceeding 5% of the formulation. Also noteworthy was that neither Mn, Ni, or Cd metals (Table 4), nor their compounds, were listed as prohibited or permitted fireworks chemicals by AFSL.

Other metals that were found at high concentrations are well-known color producers in fireworks. Examples include Bi and Sr for producing blazing reds, Cu compounds for blues, and purples from K and Rb compounds. Hazard index information for all these metals in ambient air was not yet available in the EPA RBC table[54] as of November 2011, although RBC is listed for Al (5,200 $ng/m^3$) and Ba (520 $ng/m^3$). During the 2005NY, the Al ambient air concentration of 7,295 $ng/m^3$ exceeded the hazard index, while Ba at 504 $ng/m^3$ was just below the hazard index value. Except for Rb, Ag, Ti, zirconium, and Zn, the other metals (Table 4) found in ambient air during the 2005NY were permitted by AFSL as standard fireworks chemicals.[43]

The American Pyrotechnics Association asserts that there are no Pb compounds used in U.S. manufacture; however, most fireworks products are imported from China. In 2001, AFSL began testing Chinese imports for pyrotechnic components, and those factories that did not meet standards were asked to reformulate their products to keep Pb-tainted fireworks out of U.S. markets. Recently, however, Pb and other prohibited metals were still detected in combusted fireworks in a study conducted under controlled conditions in Seattle, Washington.[55] Detection of Pb in ambient air in this study confirmed that some consumer fireworks being used, and perhaps sold in some U.S. states including Hawaii, were not AFSL tested and were probably illegal. In Hawaii, an increasing trend in fireworks imports with declining sale of consumer fireworks permits may have further indicated illegal fireworks trade. Moreover, high Pb-to-TSP ratios during the 2005NY and 2009NY–2011NY celebrations indicated that Pb-tainted fireworks were still being used or sold in Hawaii in recent years.

Lower Pb-to-TSP ratios during 2004 and 2007, and a decreasing trend during 2009NY–2011NY, could potentially be explained by differences in composition, more efficient AFSL inspection, and/or stricter implementation of the fireworks law.

Rapid dissipation rates of the $PM_{10}$ particulates are explained by the windy and isolated islands in the north central Pacific Ocean, with thousands of miles of fresh air surrounding the state. Ultrafine particles including inorganic salts and some metals can remain suspended and contribute to most of the New Year celebration aerosol mass or haze. The ambient air atmospheric residence time of fewer than three days for most metallic particulates in Pearl City, Hawaii, is much shorter than the residence time of more than one week reported for another U.S. mainland city outdoor pyrotechnic display.[56] This rapid dissipation, like the $PM_{10}$ particulates, can be attributed to Hawaii's abundant fresh air, trade winds, and associated subtropical rainfall.

### Limitations

This study was subject to several limitations. One limitation was the meteorological monitoring. Wind direction, wind speed, and rain vary widely around Oahu, so conditions at the airport are not always representative of the island or the study site. Consequently, much of the variation in fireworks-associated HAP metal concentrations each year is greatly affected by weather conditions at that particular location and could have affected the data. Another limitation was the Air Toxics program methodology. The specified sampling period was from midnight to midnight, which effectively split the New Year celebration into two reporting periods (December 31 and January 1). Consequently, the total quantity of metals for the event was effectively split into two reporting periods. In other words, if air sampling covered the entire event (before midnight and after midnight), concentrations of these metals for the 24-hour sampling period would have been much higher.

## CONCLUSIONS

Although rapid dissipation rates reduce exposure, the potential health effects due to short-term exposure to high ambient levels of HAP and other metals cannot be ignored. Cancer is the second leading cause of death in Hawaii,[57] and reducing exposure to known carcinogens such as HAP metals should be a priority. The longer-term environmental impact of these pollutant metals and other fireworks fallout, which can contaminate water supplies, beaches, surface waters, soils, and agricultural products, should also be investigated.

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# Local Acts

Acute human immunodeficiency virus (HIV) infection occurs at a time of increased transmission risk due to high viral load and, potentially, low awareness of infection status. By identifying people with recently acquired infections, local jurisdictions can potentially target prevention and treatment interventions to subgroups that disproportionately contribute to the HIV epidemic. Mounting an effective surveillance system for acute HIV infection and integrating it with programmatic activity, however, is a complex and costly undertaking. In the past several years, the New York City Department of Health and Mental Hygiene has been a leader in operationalizing such a system and evaluating newer laboratory test approaches. Bodach et al. highlight operational challenges and acute infection yields from their acute HIV infection surveillance system. Empirical findings should help guide other jurisdictions in the process of mounting similar systems.

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## INTEGRATING ACUTE HIV INFECTION WITHIN ROUTINE PUBLIC HEALTH SURVEILLANCE PRACTICES IN NEW YORK CITY

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Acute human immunodeficiency virus (HIV) infection (AHI) is brief in duration, results in mild clinical illness, and is rarely diagnosed.[1–3] This phase of infection usually lasts about two to three months, and the symptoms, if any, may include fever, fatigue, and rash.[1] However, few people are diagnosed during this phase, as acute infection is relatively brief and occurs prior to the production of detectable HIV antibodies. Nonetheless, this phase has great significance to public health, being one of the most infectious phases of HIV infection and marking the beginning of a chronic, communicable infection and disease that is usually diagnosed only after a clinically silent, lengthy interval.[4] The potential for AHI to contribute to HIV transmission has been documented by public health officials in the United States,[5] and published statistical models suggest that individuals in the acute phase of HIV contribute disproportionately to sustaining the HIV epidemic.[6–8]

While AHI has been recognized as a critical time to inform patients of the need to reduce risk behaviors and perform partner elicitation, notification, and testing services,[9–11] it seems likely to take on additional significance for treatment initiation as an approach to prevention. Antiretroviral therapy (ART) is increasingly seen as a means for population-wide HIV prevention.[3] This approach to prevention, also known as the "test-and-treat" strategy, relies upon early identification of HIV infection followed by prompt initiation of ART to achieve the maximum possible viral suppression during the patient's lifetime with HIV.[12] The test-and-treat strategy is gaining attention, and its feasibility is being tested in major U.S. cities.[13,14]

The magnitude of AHI's public health significance is matched by the difficulty entailed in its detection. The diagnostic challenge posed by AHI has inspired screening efforts involving complex and expensive laboratory procedures using pooled nucleic acid amplification test (pNAAT) algorithms.[5,15,16] Programs designed to increase the ascertainment of AHI by pNAAT have been conducted and described in North Carolina,[5,17] Seattle (Washington),[18] Los Angeles (California),[19] San Francisco (California),[20] and New York City (NYC).[21] While effective in increasing the detection of AHI, such pNAAT programs are costly, and targeting their use to the highest-yield populations to maximize efficiency has been recommended.[19,22,23] In 2009, the Food and Drug Administration (FDA) approved a fourth-generation antigen (Ag)/antibody (Ab) HIV diagnostic test that is expected to make AHI screening more efficient and less expensive. Several jurisdictions, including NYC, are being funded by the Centers for Disease Control and Prevention (CDC) to evaluate the new test's ability to detect AHI compared with pNAAT. As AHI screening efforts grow in variety and scope, there will be a burgeoning need to evaluate their population impact on AHI detection.

AHI's relevance to HIV prevention efforts, and the scale and expense of programs designed to increase its detection, suggest that routine monitoring of the frequency with which AHI diagnoses are made among the larger number of newly diagnosed HIV case patients would be useful. However, despite its public health importance, AHI has not been a part of routine HIV/acquired immunodeficiency syndrome (AIDS) surveillance in the U.S.

Starting in 2008, the NYC Department of Health and Mental Hygiene (DOHMH) made detection of AHI part of routine surveillance of HIV/AIDS in NYC.[21] To our knowledge, NYC is the first jurisdiction to incorporate population-based, systematic tracking of AHI into routine HIV/AIDS surveillance, and we expect that other cities will follow as the technology for easier detection of AHI gains wider use. In this article, we build upon previously reported findings[21] by (*1*) describing the process of implementing AHI surveillance in NYC in greater depth, including refinements to our system introduced since its initial description; and (*2*) summarizing the first two years of NYC AHI surveillance data.

## METHODS

### Establishing an AHI case definition

We built on CDC's adult HIV case definition[24] so that AHI cases are a subset of all new HIV diagnoses for those aged 13 years and older. The NYC DOHMH case definition for AHI includes people with a negative or indeterminate HIV Ab test with a detectable HIV viral load (VL) result (>5,000 copies/milliliter [mL]), a negative or indeterminate HIV Ab test followed by a positive Ab test, or a physician diagnosis of AHI.[21] The threshold of 5,000 copies/mL was used to exclude potential false-positive results among individuals with a negative or indeterminate HIV Ab test. Our goal was to use laboratory criteria[25] to define AHI whenever possible; however, we also wanted to incorporate the clinical judgment involved in diagnosing AHI into our case definition. To maximize case finding, we allowed for a documented clinical diagnosis of AHI to meet the definition on that criterion alone. To understand providers' AHI diagnostic habits, we began collecting data on whether AHI cases met our definition on the basis of clinical criteria, laboratory criteria, or both. We calculated the HIV diagnosis date as the earliest among the following dates as documented in the patient's chart: indeterminate (followed up with either a detectable VL or positive Western blot [WB] test result) or positive WB test, first detectable VL, or physician diagnosis.

### Case identification

AHI case identification was incorporated into existing protocols for routine HIV/AIDS case finding, which relies primarily on mandated reporting of HIV-related events by providers and laboratories to New York State (NYS). The largest source of reports of new diagnoses is laboratory reporting, which in NYS has included all positive WB tests for HIV Ab, all VL and cluster of differentiation 4 (CD4) values, and all HIV genotype tests since 2005.[26–28] Existing protocols for case finding and confirmation prompted by reportable laboratory events are built around the matching of reportable laboratory events to NYC's population-based HIV Surveillance Registry of all reported cases of AIDS since 1981 and HIV since 2000. Incoming positive WB tests, detectable and serial undetectable VL test values, and AIDS-defining CD4 results that do not match to the HIV Surveillance Registry prompt a field investigation involving medical record review by surveillance staff to verify and collect laboratory test results, demographic and transmission risk information, and other relevant case details. Provider reports of new cases also prompt a field investigation and medical record review to ensure accurate data collection. Finally, active surveillance at several large-volume diagnosing providers by field services staff responsible for delivering HIV partner services also generates new cases.

Starting in June 2009, case records with a VL test value of ≥100,000 copies/mL and no associated positive WB test received on or before the VL test date were flagged as possible AHI on forms sent for field investigation. Field staff were told that possible AHI should prompt them to verify AHI status during their medical record review.

### Staff training and modification of data collection forms

To promote increased identification of cases diagnosed in the acute stage, we trained all field staff and modified case investigation forms. Trainings were incorporated into regularly scheduled, hour-long, biweekly meeting timeslots with all field staff. Senior staff trained field personnel in January 2008, reviewing how to recognize possible AHI during chart review from a range of scenarios, prior to the introduction of an acute/non-acute variable on the data collection form. Staff were trained to recognize combinations of negative/indeterminate Ab tests and high VL test results, and to record the AHI status of every new HIV diagnosis on the modified case investigation form (e.g., AHI/primary HIV infection at diagnosis? Yes/no/unknown). Staff were also trained to record a documented provider diagnosis of AHI and to record available patient HIV testing

history information. Trainings were also provided to field services staff, who are assigned to high-prevalence facilities in NYC for active case finding. These staff and surveillance staff informed medical reviewers of cases with combinations of laboratory tests suggestive of AHI.

**Provider outreach**

Both the Bureau of HIV/AIDS Prevention and Control and the Bureau of Sexually Transmitted Disease Control (BSTDC) worked to promote greater provider understanding of and vigilance with regard to AHI. In February 2009, BSTDC sent a Health Alert to health professionals in NYC, including physicians, nurses, and social workers, describing reported characteristics of AHI cases ascertained through the pNAAT program and urging providers to evaluate potential cases.[29] The Health Alert Network reaches about 20,000 external e-mail recipients from health-related fields. The director of HIV/AIDS Surveillance wrote a letter to NYC providers in June 2009 similarly promoting provider awareness of the clinical features of AHI and the public health importance of diagnosing infections during the acute stage. The letter also encouraged providers to clearly document AHI in the medical chart.[30] DOHMH field staff gave physicians at surveillance facilities a folder containing the letter, an NYS provider report form, and two condoms with the NYC logo.

**Intra-agency collaboration**

The HIV surveillance unit coordinated with staff managing the pNAAT screening program in DOHMH-run sexually transmitted disease (STD) clinics. Under this program, which was launched in May 2008, confidential, blood-based samples testing Ab-negative were submitted for pNAAT. Samples testing positive on pNAAT are confirmed by WB test or individual VL if >5,000 copies/mL, and BSTDC staff perform follow-up interviews, linkage to care, and partner notification.[21] BSTDC reports AHI cases detected through pNAAT to the HIV surveillance unit for timely inclusion in the HIV Surveillance Registry.

**Data cleaning and management**

We also integrated AHI surveillance into our standard quality assurance procedures for data collection, the core of which is a biweekly scan of the field investigation database for any completed field investigation forms with a missing AHI designation at diagnosis. Public health advisors were provided feedback as to completion rates of this variable to encourage full implementation of the new procedure. AHI can be misidentified as an unconfirmed HIV case because there are frequently negative HIV Ab results, prompting our medical reviewer to query the database for unconfirmed cases with high VL test results.

Given the time-sensitive nature of AHI surveillance, we had to adjust our standard data flow for timely review and analysis of AHI cases. Biweekly database scans were incorporated as an additional case-finding tool for AHI; these scans included a line list of field investigations from the previous two weeks in which an AHI diagnosis was recorded, and this line list was provided to a medical reviewer to ensure timely and correct assignment of AHI status. All cases confirmed by the medical reviewer to be AHI within three months of their HIV diagnosis date were referred to the HIV field services unit (FSU) as a case in the acute stage. FSU staff would interview the case and assist in care linkage and partner notification at non-BSTDC sites.[31]

Because of the lag between first report of possible AHI to NYC DOHMH and entry into the HIV Surveillance Registry, we created a separate database of AHI cases populated by data from the multiple sources of AHI case finding, including the reportable laboratory events database, field investigation database, provider reporting, and patient interviews. We regularly deduplicated AHI records across these sources by name and date of birth. The AHI database was created in house by our information technology support unit within a few months. The database uses a structured query language database with table views from a Web-based interface housing other surveillance databases. Prior to the availability of the database, we tracked cases using spreadsheets and imported data into SAS® for routine analyses.[32]

**Data analyses**

Data on AHI cases diagnosed from January 1, 2008, to December 31, 2009, and reported to NYC DOHMH by September 30, 2010, are included. Data from all available sources were used to classify patient's sex, race/ethnicity, age at time of diagnosis, transmission risk, and NYC borough of residence.

We present comparisons of demographic characteristics among AHI cases diagnosed in 2008 and 2009. Transmission risk categories included men who have sex with men (MSM), injection drug use (IDU) history, MSM and IDU, heterosexual transmission, other, and no risk reported (unknown). We employed standard CDC risk categorization for all but the heterosexual transmission category, which expands to include probable heterosexual risk.[33] Chi-square or Fisher's exact tests for small cells were used for comparisons, and all tests were two-sided at $\alpha=0.05$. We used SAS® version 9.1.3 for statistical analyses.[32]

## RESULTS

### Capacity for ascertaining AHI cases

From January 1, 2008, to September 30, 2010, 21 surveillance staff conducted 33,027 field investigations at 1,890 providers and facilities in NYC. Seven staff supervised field staff and reviewed completed field investigation forms, and four nonmedical surveillance administrators assigned, reviewed, and processed case investigations. Among the 33,027 field investigations, about 6,689 (20.3%) were prompted by a detectable VL, of which 1,245 (18.6%) were VL ≥100,000 copies/mL. Approximately 20 partner services staff conducted 3,482 interviews and detected 172 new cases through active surveillance.

### Case identification

***Process of case identification.*** In total, 193 AHI cases were identified by surveillance and FSU staff. Of these, 112 (58.0%) cases met the case definition on the basis of laboratory criteria and physician diagnosis (Figure). Most cases ($n$=134, 69.4%) met the AHI case definition on the basis of a negative or indeterminate HIV Ab test with a detectable VL result, with 22 of these cases also having a prior negative or indeterminate HIV Ab test within three months preceding diagnosis. A total of 46 (23.8%) cases met the definition through these latter criteria, and 35 cases (18.1%) met the definition with provider diagnosis only.

pNAAT screening identified 46 (23.8%) cases overall. Two cases were found retrospectively through the medical reviewer's scan of the field investigation database of individuals assigned unconfirmed case status with later high VL results. The possible AHI flag was marked on 32 forms for AHI cases; 28 (87.5%) had an accompanying provider diagnosis of AHI recorded in the chart, but four (12.5%) did not (data not shown).

During 2008–2009, more than 1,103 distinct providers and facilities citywide reported 7,673 newly diagnosed adult and adolescent cases of HIV. Of these, 81 providers—including seven DOHMH STD clinics conducting pNAAT screening, 22 hospitals, 50 freestanding and university clinics, one correctional facility, and one clinical trial—diagnosed at least one AHI case (data not shown).

### Description of confirmed AHI cases

By September 2010, a total of 193 cases diagnosed during 2008–2009 were detected in the acute stage of HIV infection (Table). AHI cases were a median age of 32.0 years (range: 15–68 years) at the time of diagnosis (data not shown), and the vast majority of cases (94.8%) were male. More than three-quarters ($n$=149, 77.2%) of AHI cases reported MSM-only or combined MSM and IDU risk.

From 2008 ($n$=77) to 2009 ($n$=116), the number of AHI cases overall increased 50.6%. However, the increase was only observed among males; five females were diagnosed during each year. Cases' risk distribution was similar in 2008 and 2009, with most cases having MSM-only risk. There were no statistically significant demographic differences between cases diagnosed in 2008 vs. 2009.

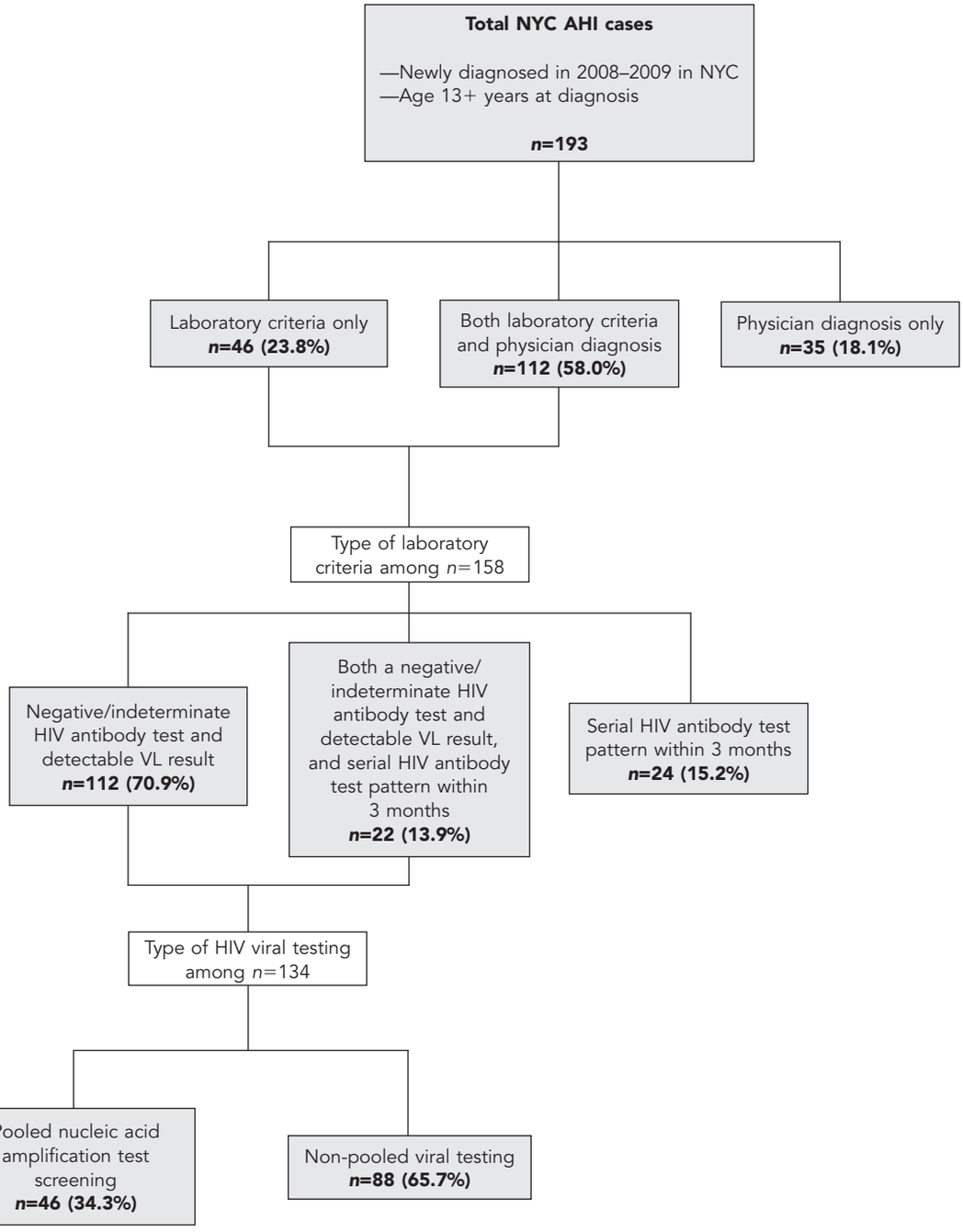
## DISCUSSION

NYC DOHMH successfully incorporated AHI detection into routine HIV surveillance beginning in 2008. As laboratory tests capable of distinguishing AHI from longer-standing HIV infections become more efficient and available (i.e., HIV Ag-Ab combo assay), and as initiatives to increase HIV testing begin to have their intended effect of diagnosing HIV earlier in its course, we think it should be more feasible for other jurisdictions to engage in similar efforts to conduct AHI surveillance.

Based on our experience, we have identified the following conditions as key to the successful implementation of AHI surveillance: (*1*) full range of reportable HIV-related laboratory results (i.e., positive WB tests, all VL tests, all CD4 tests, and all viral nucleotide sequence results); (*2*) electronic laboratory reporting for more timely report and ease of processing the high volume of reportable results; (*3*) close relationship with STD clinics and other facilities performing AHI screening through pNAAT or other means; (*4*) close integration between surveillance staff and active surveillance at the highest-volume HIV clinics; (*5*) sophisticated information technology and analytic infrastructure, especially skilled data management and programming staff; and (*6*) staffing, especially doctors, to train data collectors and conduct outreach among providers. These components, especially electronic laboratory reporting, information management, and pooled testing, are most applicable and necessary for scaling up in high-morbidity jurisdictions with well-developed surveillance systems. Surveillance jurisdictions with lower volumes of laboratory reports received may be able to replicate systems to detect test result patterns consistent with AHI using less sophisticated systems. Any jurisdiction interested in scaling up would benefit from strengthening relationships between surveillance staff and providers at STD and HIV clinics.

Given the absence of a national AHI case definition at the time we initiated our AHI surveillance, we established a local definition to guide our efforts.

**Figure. Flow chart of total NYC acute HIV infection cases diagnosed in 2008–2009, by case definition criteria**




NYC = New York City
HIV = human immunodeficiency virus
AHI = acute HIV infection
VL = viral load

**Table. Total acute HIV infection diagnoses among adolescents and adults aged 13 years and older in NYC, 2008–2009[a]**

| | AHI diagnoses | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | By diagnosis year | | | | | | |
| | | | 2008 | | | 2009 | | | |
| | Total | | | | | | | | Rate per 100,000 population |
| | N | Percent | N | Percent | Row percent | N | Percent | Row percent | |
| Total | 193 | 100.0 | 77 | 100.0 | 39.9 | 116 | 100.0 | 60.1 | 2.9 |
| Sex | | | | | | | | | |
| Male | 183 | 94.8 | 72 | 93.5 | 39.3 | 111 | 95.7 | 60.7 | 6.0 |
| Female | 10 | 5.2 | 5 | 6.5 | 50.0 | 5 | 4.3 | 50.0 | 0.3 |
| Race/ethnicity | | | | | | | | | |
| Non-Hispanic black | 64 | 33.2 | 29 | 37.7 | 45.3 | 35 | 30.2 | 54.7 | 4.1 |
| Non-Hispanic white | 71 | 36.8 | 20 | 26.0 | 28.2 | 51 | 44.0 | 71.8 | 2.9 |
| Hispanic | 52 | 26.9 | 25 | 32.5 | 48.1 | 27 | 23.3 | 51.9 | 3.1 |
| Other[b] | 6 | 3.1 | 3 | 3.9 | 50.0 | 3 | 2.6 | 50.0 | 0.7 |
| Age group (in years) at diagnosis | | | | | | | | | |
| 13–19 | 12 | 6.2 | 6 | 7.8 | 50.0 | 6 | 5.2 | 50.0 | 1.7 |
| 20–29 | 74 | 38.3 | 30 | 39.0 | 40.5 | 44 | 37.9 | 59.5 | 5.8 |
| 30–39 | 48 | 24.9 | 24 | 31.2 | 50.0 | 24 | 20.7 | 50.0 | 3.6 |
| 40–49 | 41 | 21.2 | 10 | 13.0 | 24.4 | 31 | 26.7 | 75.6 | 3.6 |
| 50–59 | 14 | 7.3 | 6 | 7.8 | 42.9 | 8 | 6.9 | 57.1 | 1.6 |
| ≥60 | 4 | 2.1 | 1 | 1.3 | 25.0 | 3 | 2.6 | 75.0 | 0.3 |
| NYC borough of residence | | | | | | | | | |
| Bronx | 28 | 14.5 | 8 | 10.4 | 28.6 | 20 | 17.2 | 71.4 | 2.7 |
| Brooklyn | 41 | 21.2 | 21 | 27.3 | 51.2 | 20 | 17.2 | 48.8 | 2.1 |
| Manhattan | 87 | 45.1 | 32 | 41.6 | 36.8 | 55 | 47.4 | 63.2 | 6.5 |
| Queens | 29 | 15.0 | 12 | 15.6 | 41.4 | 17 | 14.7 | 58.6 | 1.6 |
| Staten Island | 0 | 0.0 | 0 | 0.0 | 0.0 | 0 | 0.0 | 0.0 | 0.0 |
| Outside NYC | 8 | 4.1 | 4 | 5.2 | 50.0 | 4 | 3.4 | 50.0 | NC |
| Transmission risk | | | | | | | | | |
| MSM only | 143 | 74.1 | 59 | 76.6 | 41.3 | 84 | 72.4 | 58.7 | NC |
| IDU history only | 6 | 3.1 | 2 | 2.6 | 33.3 | 4 | 3.4 | 66.7 | NC |
| MSM and IDU | 6 | 3.1 | 3 | 3.9 | 50.0 | 3 | 2.6 | 50.0 | NC |
| Heterosexual[c] | 11 | 5.7 | 5 | 6.5 | 45.5 | 6 | 5.2 | 54.5 | NC |
| Perinatal/other | 0 | 0.0 | 0 | 0.0 | 0.0 | 0 | 0.0 | 0.0 | NC |
| Unknown | 27 | 14.0 | 8 | 10.4 | 29.6 | 19 | 16.4 | 70.4 | NC |

[a]Based on data reported to the NYC Department of Health and Mental Hygiene by September 30, 2010. Rates are based on population from the 2000 U.S. Census. Rates based on numerators ≤10 should be interpreted with caution.

[b]Other race/ethnicity includes Asian/Pacific Islander, Native American, and multiracial.

[c]Includes people who had heterosexual sex with an HIV-infected person, an injection drug user, or a person who has received blood products. For females only, also includes history of prostitution, multiple sex partners, sexually transmitted disease, crack/cocaine use, sex with a bisexual male, probable heterosexual transmission as noted in medical chart, or sex with a male and negative history of IDU.

HIV = human immunodeficiency virus

NYC = New York City

AHI = acute HIV infection

NC = not calculable

MSM = men who have sex with men

IDU = injection drug use

Our case definition was flexible to allow for diverse testing history so that cases could include those with laboratory results ordered on different days. The NYC definition permitted a one-month window of time between the negative/indeterminate test of HIV Ab and detectable VL. CDC's revised 2008 HIV surveillance case definitions document describes a diagnosis of AHI and recommends a same-day test.[24] Other published descriptions of AHI cases have also used a more stringent definition of AHI than we employed. For example, Pilcher et al.[34] used a pooled testing algorithm for follow-up testing of specimens that were HIV Ab-negative but had detectable viral ribonucleic acid. Only a portion of the acute cases in NYC—those that were detected in DOHMH STD clinics and other select facilities ($n$=46)—were tested this way. However, we believe that our case definition is well-suited to the diverse patient population and broad range of conditions for HIV testing in NYC. Furthermore, the definition provides additional information on the duration of infection at the time of diagnosis. In the future, we hope to incorporate refinements to distinguish early infection (approximately 6–24 months after HIV acquisition) from AHI. A national case definition for AHI would foster greater recognition among providers and unify local definitions. To this end, CDC established a working group to develop a national AHI case definition for surveillance.

The forthcoming AHI case definition should facilitate physician diagnoses of AHI. However, reporting mandates that do not include negative and indeterminate testing may lead to undercounting of AHI cases. Among the 7,673 new adult and adolescent diagnoses of HIV in 2008–2009, approximately 37% had a quantitative VL test available in the same calendar month as the HIV diagnosis date. We acknowledge that surveillance of AHI would be more complete if all laboratory tests, including negative and indeterminate HIV screening test results, were routinely reported to NYC DOHMH. However, the sheer volume of test data received would be burdensome for processing on a daily basis. The currently reportable laboratory events capture at least some AHI cases through VL test result reporting without being overly burdensome. Nevertheless, our expanded surveillance was facilitated by the providers who diagnosed AHI, enhanced testing detection methods, and increased HIV testing. We were able to detect cases because of provider documentation of AHI in the chart or a sequence of HIV-related tests that enabled the identification of AHI, despite the lack of mandates to report negative and indeterminate HIV tests.

However, AHI surveillance is limited by the quality and accuracy of detection methods. While nearly one-quarter (23.8%) of our cases in 2008–2009 were detected via pNAAT screening, this testing approach is typically available only in settings with a high prevalence of HIV testing. The recent FDA approval of the combination Ag-Ab assay will likely increase the number of AHI cases that we detect by enabling expansion of AHI testing to additional settings. Fostering our citywide AHI surveillance includes DOHMH HIV testing campaigns such as "The Bronx Knows" and the expansion to "Brooklyn Knows," which seek to test all adolescents and adults in NYC boroughs. NYS has revised its HIV testing law as of July 30, 2010, to allow verbal consent,[35] whereas only written consent was previously accepted. The testing initiatives, modified consent law, and AHI screening efforts in the pipeline are expected to enhance the clinical detection of AHI and AHI surveillance moving forward.

We believe that a combination of better-trained staff, more informed providers, and additional DOHMH STD clinics implementing pNAAT may have allowed for increased AHI ascertainment from 2008 to 2009. DOHMH staff conducted outreach to providers about possible AHI cases, and the provider letter and Health Alerts from the DOHMH contributed to better awareness among providers.

While we were able to detect 193 cases of AHI, this number represents <3% of all new diagnoses, suggesting that most HIV diagnoses in NYC occur after the acute stage of infection. With the time frame of acute infection being so short and diagnosis relying on provider recognition and test result patterns, detection is challenging. AHI detection may be increased by frequent testing, and prevention efforts that encourage testing can help improve the yield of AHI surveillance. We have found that HIV prevention and AHI surveillance are multifaceted, linked endeavors. Prevention activities supported by DOHMH promote early diagnosis of HIV and, thus, increase our potential to detect AHI, while our AHI surveillance provides a benchmark for prevention programs through the detection of acute and early infection and facilitates future program planning. Simply having this baseline count of cases that are detected earlier informs prevention activities and will support a test-and-treat prevention strategy.

AHI cases are different than other new HIV diagnoses; we hypothesize that AHI cases are more aware of their risk and have greater knowledge of and access to HIV testing. Risk awareness may be one explanation for the high proportion (77.2%) of those with reported MSM or MSM and IDU transmission risk. To the extent that clear differences between people being diagnosed with AHI and other newly diagnosed HIV cases can be described, people who are likely to be in the former

group would be an ideal group to whom preexposure prophylaxis (PrEP) should be targeted, as whoever receives PrEP should be at high risk for infection, yet willing to adhere to and also likely to follow up with additional testing after exposure.[36,37]

## CONCLUSIONS

Detecting individuals in the acute stage of HIV infection should be a priority for health departments, given the timely opportunity to prioritize partner notification services and linkage to care for these individuals. At a national level, amending reporting laws to include the full range of HIV-related test results in all jurisdictions and adding AHI to the national HIV surveillance case definition of the stages of HIV illness among adults and adolescents are needed to set the stage for AHI surveillance at the local level. In NYC, existing reporting laws, staffing infrastructure, and other prevention activities supported an expansion of routine surveillance. We prioritized our partner services resources to notify sex- and needle-sharing partners of acute cases of potential exposure and provide HIV testing. Also, if necessary, we provide care linkage to help schedule appointments and provide transportation for acutely infected cases through the support of our existing field services program[31,38] and disease intervention specialists of BSTDC.

We are continuing AHI surveillance, building the program, and reporting on AHI case detection in our routine HIV surveillance reports. We have begun expanding our surveillance to assess more specific risk behaviors around the time of infection among those who are acutely infected. In addition, the agency is preparing to evaluate new testing technologies to improve AHI detection. The availability of empirical data on AHI can improve our understanding of the distribution and extent of the HIV epidemic in NYC, suggest avenues for outreach to the clinical community, and help target prevention resources and programming.

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# Law and the Public's Health

This issue of *Law and the Public's Health* examines consumer rights in health insurance and the role of the external appeals reforms in the Patient Protection and Affordable Care Act (ACA). Access to a fair and impartial external appeals process is a fundamental aspect of health insurance coverage. The ACA strengthens this fundamental protection for all insured Americans, whether covered through their employers or on an individual basis. At the same time, the external appeals process is complex and creates important opportunities for active involvement by public health, as a key dimension of public health policy and practice.

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## STRENGTHENING APPEALS RIGHTS FOR PRIVATELY INSURED PATIENTS: THE IMPACT OF THE PATIENT PROTECTION AND AFFORDABLE CARE ACT

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The ability to secure a timely, fair, and balanced review of the denial of a claim for health insurance coverage is an essential element of any health insurance system. This installment of *Law and the Public's Health* reviews how the Patient Protection and Affordable Care Act (hereinafter, the ACA)[1] modifies the appeals procedures that apply to privately insured patients and discusses the implications of these reforms for public health policy and practice.

### BACKGROUND

Health insurance coverage is provided through three major sources: health plans sponsored by public and private employers, non-employer individual and small group plans sold directly by private insurance companies (a sector regulated by state law and expected to experience significant growth under the ACA through the sale of affordable plans sold in state-based health insurance Exchanges)[2] and hereinafter referred to as the "individual market," and public health insurance programs such as Medicaid and Medicare. (The legal rights of participants in Medicaid and Medicare flow from a separate and distinct legal framework from the private insurance market, and the regulations that govern appeals processes for these programs are not addressed in this article.)

Appeals of claim denials in the employer and individual markets represent a basic policy challenge because of the inherently unbalanced nature of the relationship between insurers and claimants. Insurance provisions often are obscure and incomplete, insurers themselves oversee the initial stages of the appeals process, and the basis for denied claims can be difficult to understand. In addition, insurance companies and health plan administrators are necessarily well versed in every facet of the appeals process, while the consumer, in most instances, is engaging in the appeals process for the first time.

The challenges are particularly great in the case of employer-sponsored health benefit plans. Virtually all private employer-sponsored health plans are governed by the federal Employee Retirement Income Security Act (ERISA) and fall into two categories: (*1*) fully insured ERISA plans (where employers purchase insurance coverage for their employees from an insurance company) or (*2*) self-funded ERISA plans (where the employer acts as the insurer, creating his/her own health plan and paying health-care claims with his/her own money). For both kinds of ERISA plans, courts are typically highly deferential in how they treat decisions by plan administrators regarding both the meaning of plan terms and how those terms apply to the facts of a particular case.[3,4]

The appeals process begins after the insurer denies a claim, either because (*1*) the treatment sought is simply not covered by the policy; or (*2*) even if covered, the treatment is not deemed necessary for the patient given the medical facts of the case. The patient may then challenge this decision through an internal appeals process, requesting that the insurer reconsider its decision. If the insurer upholds its initial adverse determination, the patient can pursue external appeals rights, whereby an impartial third party reviews the denial for fairness

and accuracy. In both instances, the patient requires the assistance of his/her health-care provider, as coverage decisions are based on an evaluation of the stated diagnoses and prescribed medical treatments, and challenging denials requires further justification from treating physicians and other providers.

Prior to the ACA's enactment, rights to appeal at both the federal and state level contained significant limitations. Fully insured ERISA plans and plans purchased on the individual market had weak internal appeal requirements, and external appeal rights varied from state to state.[5] Additionally, self-funded ERISA plans, representing more than half of ERISA health plans overall, were entirely exempt from providing any external review rights.[6]

Prior to the ACA, plans governed by ERISA allowed plan administrators to withhold critical documents, delay the determination process, and issue denials without a thorough explanation of the terms of coverage and why payment was not justified by the facts of the case. ERISA did not require health plans to give claimants access to an impartial external appeal system, and to the extent that state laws did provide such rights, such laws tended to be weak, and self-funded ERISA plans (i.e., plans funded by the employer but typically overseen by a third-party administrator such as a large insurance company) were exempt.

When appeals processes fail, patients generally have the right to file a lawsuit as a last resort.[7] However, litigation is both slow moving and costly, the law prevents patients injured by the denial of coverage by any ERISA plan from recovering damages for the injuries they sustain,[8] and consumers face additional challenges due to the judicial deference noted previously.

## THE ACA REFORMS

The ACA does not remove ERISA's bar against damages for injuries caused by the wrongful denial of coverage by plan administrators. Instead, the Act introduces significant reforms in the process used to review claims in an attempt to level the playing field among consumers, insurers, and plan administrators. With the exception of "grandfathered" plans (i.e., plans that were in effect March 23, 2010—the day the ACA was signed—and not subject to some of the insurance reforms contained in the legislation),[9,10] the ACA reforms apply in both the employer and individual health plan markets, including the ERISA plan marketplace.

### Internal appeals

The ACA strengthens internal appeals rights in both the employer and individual plan markets to create fairer systems when patients seek to challenge claim denials. The Act extends these stronger protections to cover the individual insurance market as well as group health plans.[11]

Additionally, the ACA broadens the right of patients to appeal benefits denied by health plans, legally referred to as "adverse benefit determinations." Prior to the ACA, the definition of an adverse benefit determination included any failure to pay for services because the health plans asserted that the patient was not eligible for coverage, the service requested was not part of the benefit plan, or the denial was based on an exclusion such as a preexisting condition. Adverse benefit determinations also included denials, reductions or termination of benefits, or claim denials based on the assertion that the requested services were either experimental or not medically necessary. The expanded definition creates a right of appeal for policy rescission (i.e., the retroactive cancellation or discontinuance of coverage) and eligibility determinations for children 19 years of age or younger who are denied coverage based on a preexisting condition.[12]

The ACA also augments the regulations that govern ERISA group plans with additional consumer protections. Regulations require consumers to receive a full and fair review of denied claims. To that end, plan administrators must now disclose the evidence reviewed and the rationale relied upon when making an adverse decision, and allow consumers reasonable time to respond. Information must be provided at no cost to the consumer, and to ensure these new disclosures are meaningful, notices regarding appeals now must be provided in a "culturally and linguistically appropriate manner." That is, notices must be provided in any language other than English in which a threshold number of plan participants are literate.[13]

To further counter the deference given to ERISA plan administrators, the ACA also includes new conflict-of-interest safeguards, prohibiting plans from providing financial or other incentives to personnel to bolster benefit denial rates. Finally, and perhaps most significantly, in the event that a denial involves the reduction or termination of treatment, plan administrators must continue to provide coverage for ongoing care pending the outcome of the internal appeal.[13]

### External review reforms

An external review allows an objective third party to review the appropriateness of a decision made by the insurer or plan administrator. Similar to the extension of existing internal appeal rights to cover the individual market, the ACA extends external review rights to all ERISA employer-sponsored group health plans. The

ACA also broadens the basis for bringing an external review under state law.[14]

Originally, federal regulations implementing external review reforms under the ACA allowed for the review not only of the facts of the case, but also the manner in which plan administrators had interpreted the terms of their coverage documents, thereby allowing an independent review of the meaning of the terms of coverage. This allowance provided a strong countervailing force to the broad deference given plan administrators who were interpreting plan documents. Final federal regulations retreat on this issue, however, limiting independent external reviews to decisions that require the exercise of "medical judgment" (i.e., decisions related to clinical treatment and levels of care), and excluding from most external reviews issues related to interpretation of plan language and errors related to claims processing.[15–17] Nevertheless, on a national level, the new standards still represent an improvement and impose a broader basis for external review than previously available in most states.

Under the ACA, state external review systems must meet the minimum consumer protections outlined in the Uniform External Review Model Act issued by the National Association of Insurance Commissioners.[18,19] These protections, in many instances, will be more robust than existing state legal standards. They include longer timelines for requesting a review, require the cost of reviews to be covered by the health plan, and prohibit minimum dollar amounts for challenging disputed claims. For the first time, the ACA also extends mandatory external appeal protections to self-funded ERISA plans, representing a substantial expansion of consumer rights and creating a new review process administered by the federal government.[20,21] It is estimated that this expansion will extend the right to external review to approximately 47 million additional Americans.[22]

The ACA external review process requires insurers and health plans to use certified reviewers who are "qualified to conduct the external review based on the nature of the health-care service that is the subject of the review,"[23] thereby ending the relatively common practice, prior to the ACA, of assigning external reviews to any licensed physician, regardless of his/her area of clinical expertise. In addition, the new ACA standards allow consumers 60 days to file an external review from the time the internal appeal is complete, which is significantly longer than time periods that were in place on the state level prior to the ACA.

## IMPLICATIONS FOR PUBLIC HEALTH PRACTICE AND POLICY

The ACA sets national standards for internal appeal and external review processes, providing consumers the opportunity to fully understand and exercise their appeal rights, but the ACA does not alter the patient's reliance on the significant administrative role of providers in the appeals process. New provisions, however, create a relatively uniform set of minimum standards for bringing administrative challenges to insurance denials where none previously existed. This uniformity provides public health professionals an opportunity to craft effective public education for consumers as well as professional training for nurse managers, patient navigators, social workers, and other advocates on the front lines of care delivery.

From a public health perspective, a transparent process for appealing improperly denied insurance claims carries direct implications for access to health care. There is a growing awareness in the health policy community that hospitals, clinics, and other provider settings need to be fully engaged in the consumer appeals process. Based on the structure of consumer appeal rights, providers are forced to act as proxy advocates for consumers, as the insurance fact-finding process relies entirely on the strength of the medical record and the diagnostic rationale of clinically prescribed care. However, attempts at mobilizing administratively burdened providers are often met with delays, as well as expressions of hostility directed at the insurance industry. Physicians and other providers rightfully argue that insurance plans have no legitimate role in the process of diagnosing and treating patients. However, the current structure triangulates physicians and health plans, with patients caught in between at the exact moment they require access to care.

The challenge from a policy perspective is more complex. One option, regardless of political or economic ideology, is to create additional systemic reforms that shift the mechanism for controlling health costs from utilization review of insurance plans, closing the chasm that exists among the delivery of care, the specificity of a particular patient's needs, and the practicality of how to cover the associated costs. Far more expedient, and politically realistic, is fostering a culture among providers and within delivery-of-care models that enhances the natural partnership existing between patients and their health providers. Such a policy shift would necessitate creating structural changes across provider settings to simplify consumer access to the knowledge and documentation necessary to challenge insurance claim denials.

The ACA reforms allow clinicians and health-care providers a greater voice in the appeals process on their patients' behalf by imposing mandatory disclosure of both the evidence and rationale for decisions made by plan administrators. Now, when patients turn to providers for the necessary expertise and documentation to challenge these determinations, providers can more efficiently and effectively address the objections raised by insurance plans. Integrating the knowledge and skills required to navigate the consumer appeals process at the provider level is a natural extension of the trend to provide navigational support to patients, and is no less important than helping patients navigate complex medical bureaucracies or adhere to multifaceted clinical protocols. Significantly, prior to ACA reforms and despite challenges associated with the process, success rates for appeals have been documented at more than 50% and, although imperfect, these reforms provide consumers an even greater likelihood of success.[24]

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# NCHS Dataline

A new report from the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC) takes a long view—75 years—of mortality in the United States. Data will soon be available from the 2011 Survey of Pathways to Diagnosis and Service, a large-scale, nationally representative survey of children with learning and developmental conditions conducted by NCHS. A new study reports the results of questions regarding the economic burden of illness, which were added to the National Health Interview Survey in 2011. The latest data on the prevalence of obesity show little change from the previous survey two years earlier, with obesity levels remaining relatively constant.

## 75 YEARS OF U.S. MORTALITY

Year by year, changes in mortality are regularly tracked and can be important indicators of the health and well-being of a population, but long-term trends have the potential to showcase the major shifts and swings in mortality and population patterns. Through an examination of long-term mortality trends, the impact of changes in health care, disease diagnoses, and treatment; the development of drugs including antibiotics; technological advances; public health and prevention initiatives; and sociological and population shifts can be identified and studied. A new NCHS report, "75 Years of Mortality in the United States, 1835–2010,"[1] does just that, using data from the National Vital Statistics System. This new report presents data by age, gender, and race/ethnicity and points to a number of key findings during this 75-year period.

The number of deaths increased by more than one million from 1935 to 2010, but the age-adjusted (to account for the rising age of the U.S. population) risk of dying dropped 60% from 1935 to 2010. The risk of dying decreased for all age groups but was greater for younger age groups, with a 94% reduction in death rates for those aged 1–4 years compared with a 38% decline for those aged ≥85 years. Age-adjusted death rates were consistently higher for males than for females (e.g., the rates were 65% higher for males than for females between 1975 and 1981 compared with 40% higher for males than for females in 2010), although the rates for males and females each decreased substantially from 1935 to 2010. The risk of dying decreased for all racial/ethnic subgroups of the U.S. population from 1935 to 2010; however, differences persisted among groups (i.e., the gap was the widest between 1988 and 1996).

The report shows that heart disease, cancer, and stroke were among the five leading causes of death every year from 1935 to 2010, with heart disease and cancer being the first and second leading causes of death each year during that period. Data presented in this report were based on information from death certificates filed in states and the District of Columbia and compiled into national data by NCHS.

## SURVEY OF PATHWAYS TO DIAGNOSIS AND SERVICE

Data will soon be available from one of the largest nationally representative surveys to gather information on the diagnosis, treatment, and other aspects of autism spectrum disorder, developmental delay, and intellectual disability among school-aged children. The Survey of Pathways to Diagnosis and Service was designed to help researchers and policy-makers better understand the processes by which learning and developmental conditions in children are diagnosed and treated. The Pathways Survey also aims to describe the types of services that children with these conditions use, identify any problems getting needed health care, and collect important information about the parents' experience in the diagnostic and treatment process.

School-aged children who have or once had a diagnosis of developmental delay, autism spectrum disorder, or intellectual disability were identified from the 2009–2010 National Survey of Children with Special Health Care Needs. The Pathways Survey followed up with parents of these children by asking them to participate in a telephone interview and complete a mail questionnaire. Parents were asked about the original diagnosis, a history of other diagnoses and clinical service use, current educational service use, their perceptions of disorder and service effectiveness, and current symptomology and impairment levels.

The survey was sponsored by the National Institute of Mental Health (NIMH), National Institutes of Health. NIMH, NCHS, the Maternal and Child Health Bureau, the Health Resources and Services Administration, and CDC's National Center on Birth Defects and Developmental Disabilities were involved in the survey planning process. A committee of federal and academic experts identified key research questions and crafted

the content of the questionnaire. Data for the survey were collected from February to September 2011, with a sample size of approximately 4,000 children aged 6–17 years whose parent or guardian completed the 2009–2010 National Survey of Children with Special Health Care Needs and reported that the child had or once had a diagnosis of developmental delay, autism spectrum disorder, or intellectual disability. More information about the survey is available at http://www.cdc.gov/nchs/slaits/spds.htm. When findings are available, instructions on obtaining the data will also be available.

## FINANCIAL BURDEN OF MEDICAL CARE MEASURED IN 2011

In 2011, three new questions addressing the financial burden of medical care were added to the National Health Interview Survey (NHIS) family component. The NHIS is a large-scale, general-purpose health survey that gathers data from a representative sample of the civilian, noninstitutionalized population on an annual basis. Topics of current interest are added to the survey periodically. The questions on economic burden addressed problems paying medical bills, paying medical bills over time, and having medical bills that cannot be paid at all. "Financial Burden of Medical Care: Early Release of Estimates from the National Health Interview Survey, January–June 2011"[2] provides preliminary estimates of the financial burden of medical care among the U.S. population by selected demographic variables including gender, age, poverty status, insurance coverage, and race/ethnicity.

During the first six months of 2011, one in three people lived in a family that was experiencing the financial burden of medical care, one in five people lived in a family that was having problems paying medical bills, one in four people lived in a family that was paying medical bills over time, and one in 10 people lived in a family that had medical bills that they were unable to pay at all. The likelihood of having financial burdens declined with age: 21% of adults aged 18–64 years, 10% of adults aged 65–74 years, and 7% of adults aged 75 years and older reported having problems paying medical bills. Among those younger than 65 years of age, those who were poor and those who were near poor were more likely to live in families having problems paying medical bills and to have medical bills they were unable to pay at all than those who were not poor. More than one in five poor and more than one in five near-poor people younger than 65 years of age were in families that had medical bills they were unable to pay at all. Among adults aged 65 years and older, those who were poor and those who were near poor were more than three times as likely as those who were not poor to be in families that had problems paying medical bills in the past 12 months.

Insurance coverage had a direct impact on a family's financial burdens. For people younger than 65 years of age who were in families without insurance coverage, 46.7% reported having some type of financial burden, either paying late, paying over time, or being unable to pay at all. This percentage dropped to 30.4% for those with private insurance and 38.7% for those covered by some form of public insurance (e.g., Medicaid, Children's Health Insurance Plan, state-sponsored or other government-sponsored health plan, Medicare [disability], and military plans). Looking at racial/ethnic differences for people younger than 65 years of age, those in families with financial burdens ranged from 40.5% for non-Hispanic black families to 36.2% for Hispanic families, 34.4% for non-Hispanic white families, and 17.2% for Asian families.

## 2009–2010 ESTIMATES OF OBESITY PREVALENCE RELEASED

The latest data from the National Health and Nutrition Examination Survey (NHANES) collected in 2009–2010 show little change in the prevalence of obesity for adults and young people from the 2007–2008 estimates. More than one-third (35%) of adults were obese in 2009–2010. There was no difference in the prevalence of obesity between adult men and women at any age. Among women, the rates of obesity were higher for those aged 60 years and older (42.3%) than for those aged 30–39 years (31.9%). Almost 17% of young people (aged 2–19 years) were obese in 2009–2010; boys were more likely than girls to be obese (18.6% vs. 15.0%, respectively). Looking at trends during the past decade, obesity increased for men and boys but not for women and girls from 1999–2000 to 2009–2010.

NHANES collects data from a nationally representative sample covering all ages of the civilian, noninstitutionalized population through personal interviews, standardized physical examinations conducted in mobile examination centers, and laboratory testing. The report, "Prevalence of Obesity in the United States, 2009–2010,[3] is available on the NCHS website at http://www.cdc.gov/nchs/data/databriefs/db82.htm.

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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For updates on the work of the task force and subsequent reports and products, see http://www.asph.org/FramingtheFuture. The sponsor of the task force, the Association of Schools of Public Health (ASPH), welcomes ideas, comments, and questions from *Public Health Reports* readers on the project blog at **http://framingpublichealtheducation.typepad.com/**.

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