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Editorial: Funding and Implementing Routine Testing for HIV

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Source: *Clinical Infectious Diseases*, Vol. 45, Supplement 4. Opportunities for Improving the Diagnosis of Prevention of and Access to Treatment for HIV Infection in the United States (Dec. 15, 2007), pp. S244-S247

Published by: [Oxford University Press](#)

Stable URL: <http://www.jstor.org/stable/4464255>

Accessed: 15/07/2014 15:17

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# Funding and Implementing Routine Testing for HIV

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The toll of death and human suffering caused by HIV/AIDS during the past 25 years is made all the more tragic by the fact that lifesaving antiretroviral therapies remain available to only a fraction of those who need them worldwide. In the United States—the richest and most powerful nation on Earth—lack of access to treatment for HIV infection seems inexplicable. Yet 500,000 Americans living with HIV infection—approximately half of all HIV-infected people in the United States—do not receive the ongoing medical care they so desperately need [1]. This assessment includes the staggering estimate that 1 in 4 individuals are believed to be unaware they are infected with HIV [2].

It is no wonder then that the Centers for Disease Control and Prevention (CDC) unveiled broad new recommendations in late 2006 that urge the nation's health care professionals to routinely offer voluntary HIV testing to their patients aged 13–64 years, regardless of identified risk factors [3]. Among the ills the CDC hopes to address with its new recommendations is the large number of individuals—predominantly people of color and women—who receive a diagnosis of end-stage AIDS shortly after learning they are

HIV positive. Tragically, early screening, access to health care, and access to support services for these individuals might have prevented the onset of advanced disease and vastly improved their lives.

The call for intensified efforts to identify individuals with previously undiagnosed HIV infection and link them with lifesaving health care and support services was roundly applauded by physicians, public health officials, patient advocates, members of the press, and AIDS organizations. Indeed, people and agencies on the front lines of the epidemic—those living with or at risk for HIV disease, AIDS activists, and AIDS organizations—universally agree on the importance of helping reach people with undiagnosed HIV infection.

However, many community stakeholders oppose the CDC's recommendation that health care settings use “opt-out” screening as the optimal way to expand the offer and acceptance of voluntary HIV testing. According to the CDC, opt-out screening differs from opt-in screening because it presumes that patients consent to testing unless they explicitly decline to be tested. In addition, the CDC's operational definition of opt-out screening eliminates the need for separate written consent and makes pretest prevention counseling optional.

## IS OPT-OUT THE BEST WAY TO EXPAND TESTING?

Community stakeholders, whose advocacy is critical for widespread adoption of expanded testing policies, overwhelmingly support written, informed consent as a

means to ensure that individuals have fully considered the implications of an HIV-positive test result prior to accepting testing. In addition, groups voiced concern that elimination of pretest counseling might disadvantage some at-risk individuals who test negative for HIV but are not educated about their risk behaviors or counseled to reduce them. In March 2006, fifty-four local, regional, and national organizations signed a joint letter to the CDC, expressing their concerns with the elimination of written, informed consent and pretest counseling and urging federal officials to retain these stipulations in its revised recommendations [4].

A diverse set of organizations, including the American Civil Liberties Union, the Community HIV/AIDS Mobilization Project, and Gay Men's Health Crisis, commented that written, informed consent has not been shown to discourage HIV testing acceptance and that it serves the valuable and necessary purpose of protecting patients against uninformed and involuntary testing [5–7]. Groups further urged federal and state officials to invest in increased training and technical assistance for clinicians and health care administrators to ensure that expanded testing efforts are of the highest quality and adhere to generally accepted standards of ethical practice. These standards include ensuring that testing services are accessible, accurate, confidential, fully voluntary, and conducted free of coercion; informing test subjects about the meaning and consequences of an HIV-positive test result, the ways HIV transmission can occur, and

Presented in part: Opportunities for Improving HIV Diagnosis, Prevention & Access to Care in the U.S., Washington, D.C., 29–30 November 2006.

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**Clinical Infectious Diseases** 2007;45:S244–7

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1058-4838/2007/4512S4-0008\$15.00

DOI: 10.1086/522545

how transmission can be prevented; providing or making readily available comprehensive HIV counseling and education; and, for persons with positive results of an HIV test, providing counseling about their diagnosis and appropriate linkages and referrals so they may access HIV-related health care and support services.

## COMMUNITY CONCERNS

Although the CDC's revised recommendations include many of the positions stated above, community groups voiced concern that some health care settings less experienced in HIV testing and related services might adopt substandard testing protocols, thereby disadvantaging or harming their patients. For example, the National Association of People with AIDS (NAPWA) commented in a written statement that "[w]hile NAPWA supports CDC's initiatives for expanded HIV screening, we must be assured that the removal of written informed consent does not result in involuntary HIV testing without the ability to decline" [8, p. 3], and the National Black Leadership Commission on AIDS wrote that "[c]ounseling is an important responsibility for physicians who must be trained to do so effectively and should not be eliminated from the patient/physician protocol in HIV/AIDS testing and treatment" [9, p. 3]. A joint statement from 33 community groups regarding the CDC's new recommendations explained that opt-out screening may not be indicated for certain populations, because "[d]e-linking counseling from testing is highly problematic for many vulnerable populations. For example adolescents and young people, who are at particularly high risk of stigma and rejection from family and friends when disclosing their HIV status and who are often dependent on adults to access health care services and reimbursement, may not be fully prepared for the consequences of an HIV diagnosis in the absence of counseling and written, informed consent" [10, p. 1]. Even advocates representing vulnerable populations most likely to benefit

from expanded HIV testing efforts voiced reservations about routine opt-out testing methods. "In communities of color, these guidelines will focus on emergency rooms—about the worst place to receive an HIV test there's almost no confidentiality, much less careful explanations," said Mark McLaurin, executive director, New York State Black Gay Network, during an October 2006 community conference call on the revised HIV testing recommendations, hosted by the Community HIV/AIDS Mobilization Project.

Notably, several pilot programs have demonstrated the viability of voluntary HIV testing—performed with strong confidentiality protections, pretest counseling, written informed consent, and linkage to appropriate referrals—in emergency departments [11]. Successful models rely on strong administrative and clinical leadership, training and technical assistance, increased staffing, and dedicated funding to sustain the effort.

In summation, community groups have challenged a perceived underlying principle of the CDC's revised testing recommendations, namely, to value quantity over quality. In making their critiques, community groups assert that expanded and routinely offered HIV testing can and must be achieved without shortchanging vulnerable populations of health education, informed written consent, and linkage to care and support services they so desperately need and deserve. Moreover, real progress against the epidemic will require more than just identifying additional HIV-positive people. Expanding prevention education and treatment access and preserving human rights remain as important or, arguably, more important than merely expanding testing. "Data show most people offered testing accept it... We should not be doing this on the cheap," said Congresswoman Donna Christian-Christiansen (Democrat, US Virgin Islands), echoing community sentiments that calls for routine testing should not pave the way for lower-quality or unethical testing programs [12].

## IMPLEMENTATION: THE DEVIL IS IN THE DETAILS

In rejecting the recommendation for wide-scale opt-out screening, community groups argue that a single testing approach is simply unsuitable for all settings, populations, and clinical contexts. Policy makers and AIDS advocates should therefore pursue a wide variety of approaches in order to expand the offer and acceptance of voluntary HIV testing. Moreover, AIDS advocates caution policy makers and health care planners to remain focused on the ultimate goal of reaching people with undiagnosed HIV infection. Opt-out testing remains a means to an end but not an end in itself.

Various groups in Illinois, including the AIDS Foundation of Chicago, have documented how inadequate public financing for HIV testing and treatment campaigns has played a significant role, if not the most significant role, in limiting the availability of HIV testing. An informal survey of various Illinois health care organizations, for example, documented that, without additional resources, limitations in infrastructure and treatment capacity will restrict the expansion of testing (AIDS Foundation of Chicago, unpublished data). Officials with the Chicago Department of Public Health reported turning away a mean of 200 individuals each month at their HIV-STD clinics because of insufficient capacity. The emergency department at Cook County's Stroger Hospital, which assists nearly 200,000 patients per year, estimated needing an additional \$3 million for HIV testing kits alone to implement routine HIV screening. Officials with the Heart of Illinois AIDS Clinic in Peoria, which reported testing 36% more HIV-positive people in the first 9 months of 2006 than in all of 2005, said that, without increased funding, they will have inadequate capacity to provide more testing and care services.

Decreased federal funding over the past 7 years for health care and support services provided through the Ryan White Program has put a tremendous strain on

safety-net systems for uninsured people living with HIV/AIDS. Unless Congress and President George W. Bush appropriate increased funding for HIV/AIDS treatment, service systems will simply be unable to meet the needs of persons in whom infection was newly identified through expanded testing. Already, inadequate funding jeopardizes the health and well-being of too many Americans. For example, as of May 2007, more than 500 people languished on AIDS Drug Assistance Program (ADAP) waiting lists across the country [13]. Four people died in South Carolina in 2006 waiting for access to life-saving therapy [14]. Hundreds more are ineligible for ADAP and are therefore not reflected on waiting lists.

Rather than calling for increased funding as a way to expand the offer of voluntary testing, the CDC has urged state policy makers to reform existing written consent and counseling requirements, believing that such requirements pose a significant barrier to widespread testing acceptance. Groups such as the AIDS Legal Counsel of Chicago, Lambda Legal, and the Center for HIV Law and Policy warn that changes to states' testing policies could diminish the very patient protections, including state HIV confidentiality laws, needed to encourage at-risk individuals to accept testing, care, and prevention services. Moreover, AIDS advocates argue that policy changes are unnecessary in order to expand testing.

New York City public hospitals, for example, increased the number of people tested by 63% in 2006, using a simple, 1-page written consent and HIV-testing explanation form, streamlined counseling, and rapid HIV testing. According to a Housing Works release, this measure detected more than twice as many new infections in 2006 than in the previous year and was not dependent on opt-out methods or changes to state testing policy [15].

Further successes have been observed in neonatal settings. According to the Pediatric AIDS Chicago Prevention Initia-

tive, Illinois achieved universal HIV screening among pregnant women and newborns by (1) creating an HIV perinatal hotline to facilitate appropriate medical and social service linkages, (2) developing and disseminating standardized and streamlined counseling and consent materials, (3) training 15,000 labor and delivery and nursery staff in the state's 133 birthing hospitals on HIV testing protocols (training topics included conducting HIV counseling, obtaining written informed consent, administering rapid HIV testing, and linking HIV-positive women and newborns to expert health care and support services), (4) providing technical assistance on appropriate testing procedures and HIV prophylactic care to each birthing hospital, and (5) requiring hospitals to provide monthly reports on rapid HIV tests performed. The initiative produced remarkable results, increasing the number of Illinois pregnant women and newborns who received HIV testing from 73% in 2005 to >99% in 2006 (Illinois Department of Public Health and the Pediatric AIDS Chicago Prevention Initiative, unpublished data).

Lessons from Illinois and New York can be replicated in other jurisdictions, thereby serving the CDC's central goal of encouraging non-HIV specialists to routinely offer HIV testing. By investing in training and technical assistance, state and federal officials can educate clinic leaders, nurses, physicians, and other health care workers on ways to integrate voluntary testing into routine care. The development and dissemination of standardized tools will help non-HIV specialists adopt high-quality testing protocols. States should also develop methods to help these professionals make appropriate linkages and referrals for their newly identified HIV-positive patients. Finally, any effort to change clinical behaviors should include strong data-collection and evaluation components in order to measure progress and impact.

## **REAL HARM OR REAL OPPORTUNITIES?**

In preparing these remarks, I learned not only about successes but also about remarkable failures that give us pause and serve as sobering reminders to carefully implement expanded testing. One health care professional told me about a patient who recently wandered into the emergency department where she works, with a prescription for antiretroviral monotherapy. Apparently, the young man had recently tested positive for HIV elsewhere (it is unclear whether he gave consent for testing), and instead of receiving a careful explanation of his diagnosis and a referral to an HIV specialist, the patient was given a prescription for monotherapy and told nothing more than to take it to the local emergency department to be filled. Thankfully, he received compassionate care and a detailed explanation about his new diagnosis at the hospital, but how many others were not so lucky? This and other egregious examples of substandard testing and care can and must be prevented, or a bad situation will be made markedly worse.

The rollout of revised testing recommendations has also failed to address the issue of persistent stigmatization and discrimination against people with HIV/AIDS. Although offering testing as part of routine care may actually decrease the stigmatization associated with HIV testing, people with HIV/AIDS bristle at the suggestions by the CDC and others that HIV/AIDS-associated stigmatization and discrimination has abated.

As a person living with HIV, I can attest that this viewpoint cannot be more misguided. When people first learn they are infected with HIV, the emotional and psychological issues ignited by the social stigmatization of HIV infection are, in the most literal sense, extraordinary. Although many officials would like to compare HIV screening with screening for cholesterol, heart disease, or diabetes, they are not analogous. To make such a comparison is

to betray a significant lack of understanding of what living with HIV is like today in America, and it is disturbing that such an attitude may have substance in the formation of public policy. It is certainly wished by the HIV-positive community that people living with HIV be treated in the same way that any other patient with a chronic medical condition is treated, but the reality is they are not—we are not. HIV infection is different. And that reality has to be at the forefront of our understanding, before we can determine the next step toward confronting this ongoing crisis.

### Acknowledgments

I thank Neil Canavan for his assistance with editing this manuscript.

The “Opportunities for Improving HIV Diagnosis, Prevention & Access to Care in the U.S.” conference was sponsored by the American Academy of HIV Medicine, amfAR, the Centers for Disease Control and Prevention, the Forum for Collaborative HIV Research, the HIV Medicine Association of the Infectious Diseases Society of America, and the National Institute of Allergy and Infectious Diseases. Funding for the conference was supplied through an unrestricted educational grant from Gilead Sciences, amfAR, Glaxo-SmithKline, Pfizer, Abbott Virology, OraSure Technologies, Roche Diagnostics, and Trinity Biotech.

**Supplement sponsorship.** This article was published as part of a supplement entitled “Opportunities for Improving the Diagnosis of, Prevention of, and Access to Treatment for HIV

Infection in the United States,” sponsored by the American Academy of HIV Medicine, amfAR, the Centers for Disease Control and Prevention, the Forum for Collaborative HIV Research, the HIV Medicine Association of the Infectious Diseases Society of America, and the National Institute of Allergy and Infectious Diseases.

**Potential conflicts of interest.** D.E.M.: no conflicts.

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