

# Expanding the Availability and Acceptance of Voluntary HIV Testing

## **Expanding the Availability and Acceptance of Voluntary HIV Testing:**

### **Fundamental Principles to Guide Implementation**

**June 2007**

#### BACKGROUND

Federal public health officials, recognizing that a significant percentage of people with HIV are not diagnosed until they present with AIDS-related illness, are recommending that the nation's healthcare providers offer HIV testing to all individuals from the ages of 13 to 64, without regard to identified risk factors. Officials with the U.S. Centers for Disease Control and Prevention (CDC) are currently convening advisory groups to help develop national implementation guides specific to various clinical settings. In addition, the American Academy of HIV Medicine (AAHIVM) is spearheading efforts to identify medical providers' needs in implementing the testing recommendations and to develop strategies to support those needs.

People with HIV and their care providers and advocates are also working to accomplish the important goal of expanded testing and early diagnosis, but emphasizing that ethical, science-based implementation plans, attention to the continuing health needs of people with HIV, and respect for the civil and human rights of patients must be at the heart of successful efforts to increase testing. To ensure that the important stated goals of more widely-offered testing are accomplished, a coalition of people living with HIV and the legal, medical and service organizations representing them (listed below) has framed these core principles, grounded in sound medical and public health science, ethics and human rights, to be followed by public and private decision-makers as they implement expanded HIV testing services. The fundamental elements—that HIV testing must always be informed, voluntary, confidential, and supported by health care and other services, and that it is always most effective when offered by someone trusted and trustworthy—apply to all persons, including pregnant women, youth and the incarcerated, and to testing issues beyond the current discussions about implementing the new CDC recommendations.

We urge all stakeholders and decision-makers to use these principles to inform their thinking and guide their activities around HIV testing expansion. In addition, we urge people living with HIV or AIDS, their medical and other care providers, their advocates, and policy makers to use these principles to measure the success of local, state, and national testing-expansion efforts.

This set of principles comes from discussions involving a coalition of human rights, medical, HIV service, and related organizations, and is intended to guide discussions and implementation of expanded HIV testing programs. The primary authors of the principles are the AIDS Foundation of Chicago, the Center for HIV Law and Policy, and Lambda Legal, with input from advocates around the country.

The principles are meant to inform stakeholders working on expanded testing. They are a tool to help stimulate conversations, planning, and community input. We hope that they will guide implementation discussions and call on stakeholders to consider treatment and care issues that should be linked to testing. They were conceived in the belief that everyone—consumers, community leaders, HIV/AIDS service organizations, physicians, nurses, public health and elected officials, etc—has a stake in achieving an expanded testing paradigm in a thoughtful and meaningful way that produces long-term benefits for those with HIV. The principles will be shared with state and federal public health officials, prevention planning groups, service and community organizations, media, and others.

Endorsers of these principles are deeply concerned with the extent to which the focus on “streamlined” counseling and consent for HIV is viewed as in itself sufficient to solve the problem of late HIV diagnoses and entry into treatment. Without an equivalent focus on factors such as funding, training, and evaluation, let alone patient mistrust and the benefits of informed decision-making, relatively few will benefit and some will likely be harmed. Endorsing organizations are calling for achievable testing expansion that recognizes the importance of patient autonomy and human rights, and actually reaches the undiagnosed and affords them real access to care and services.

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## **GUIDING PRINCIPLES**

The health of individuals and the public demand that HIV testing programs be fully informed, consensual, voluntary, confidential or anonymous, and supported, directly or by referrals, with appropriate education, counseling, health care, mental health care, and social services. In addition, expanded testing programs designed to reach undiagnosed people with HIV must be guided by the following principles.

### **1. People living with undiagnosed HIV infection must be reached and offered testing.**

Everyone agrees that more must be done to help the estimated 250,000 to 300,000 people in the U.S. living with undiagnosed HIV infection. In order to accomplish this goal, health care providers in widely varied settings should provide basic HIV counseling and prevention education and offer HIV testing with informed consent to many more patients, not just those who are identified or perceived to be members of HIV “risk groups.” HIV-positive people who do not identify as members of HIV “risk groups” are among those who are likely not to know their status. Regularly offering testing to patients can help eliminate the distorting effect of provider assumptions about patients’ activities and both provider and patient discomfort about risk screening related to stigmatized behaviors (such as drug use) and identities (such as being gay, bisexual or transgender).

### **2. Any HIV testing program must provide the highest standard of care.**

Promoting high quality and ethical service provision is as important in HIV testing as it is in the medical management of HIV therapies and the conduct of clinical trials. The CDC maintains in its Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings (“Recommendations”) that testing must be with the knowledge of the patient, voluntary, and free from coercion (p. 8), and states that the Recommendations “are intended to comply fully with the ethical principles of informed consent” (p. 13). HIV testing programs incorporated into clinical care settings also must “ensur[e] a provider-patient relationship conducive to optimal clinical and preventive care” (p. 7 of the Recommendations).

The call for expanded testing is an opportunity for diverse stakeholders to craft locally and culturally appropriate strategies responsive to community needs. High quality testing programs have the following indispensable elements: they are readily available, accessible, highly reliable, and confidential; services are fully voluntary and provided free of coercion; services are provided with informed consent so that those who are tested understand the nature of testing, what test results mean, and implications of a positive or negative result; testing is provided in settings where counseling and prevention education are

delivered or made readily available through effective referral systems; and all clients are provided with needed service referrals and linkages to accessible continuing care.

**3. Everyone offered testing must be educated about HIV and the significance of positive and negative test results.**

The level of understanding of HIV in the general population is still very low, and misperceptions about HIV and AIDS and the transmission of HIV continue to fuel HIV-related stigma and discrimination. Providing all of those offered testing with culturally and linguistically appropriate information about HIV and risk-reduction strategies will help reduce the misperceptions and related stigma. People are also more likely to agree to be tested and to return for follow-up care if they have more information. Everyone offered testing must be educated about the significance of positive and negative test results. Testing without counseling about the risk of false negatives can generate a dangerously false sense of security. Most people aren't aware that the greatest risk of transmission is from newly infected individuals with high viral loads who may not know that they are infected and will usually test negative in standard antibody screening. Newly-infected individuals account for nearly half of all HIV transmission, so programs must counsel those who test negative about the possibility that they could in fact be positive and at their most infectious. Moreover, some people who test negative may be at risk of becoming infected in the future and therefore will benefit from counseling about how to avoid infection. In the health care setting, appropriate counseling may best be accomplished through collaborative arrangements with qualified AIDS service and community organizations, which also are well-equipped to provide case management and referral services.

**4. People who test positive for HIV antibodies must be linked to care.**

Efforts to expand the offer and acceptance of voluntary HIV testing in order to identify undiagnosed HIV-positive individuals are not enough. The testing must be linked to genuine efforts to improve the health, lives and prospects of those with HIV. These efforts must include concrete plans to redress the inadequate access to care and services that is the reality now for many people who already are diagnosed, and specifically ensure that all people living with HIV receive the HIV-specialty healthcare and support services they so desperately need, including access to combination antiretroviral treatment when medically appropriate. As the CDC notes in its Recommendations, "HIV screening without such linkage [to prevention and care] confers little or no benefit to the patient" (p. 6). With many thousands of people already diagnosed with HIV not in care, evaluation of the impact of HIV testing policies must look beyond the numbers screened to determine the numbers connected to and remaining in care.

**5. Expanded HIV testing must be carefully planned, implemented and monitored.**

Efforts to expand HIV testing must be thoughtfully designed and proceed in ways that meet community needs, safeguard the

rights of people being tested, and help link individuals living with HIV infection with the health care, education, counseling and testing they need. If programs to expand testing are rushed into operation, they are likely to be poorly designed and badly implemented, with unfortunate results for both patients and the public health. A poorly planned expanded testing program is more likely to result in testing that is not fully voluntary and informed; this is more likely to alienate patients from the testing process and subsequent care. If effective mechanisms are not in place for linking those testing positive to care, and if health care and social services are not funded, available and accessible, little purpose will have been served. A poorly implemented program will alienate patients and reinforce the mistrust of HIV-positive people on the threshold of the health care system, with resulting harm to individuals and to the public health.

Approaches to expanded testing also must acknowledge and address the fact that many individuals already diagnosed with HIV are not receiving the minimum standard of effective care and services set forth in other federal guidelines governing treatment, and consistent with the human right to the highest attainable standard of health care. If barriers to care are not addressed, expanded testing practices will neither serve the people diagnosed with HIV nor achieve important public health goals. Monitoring to ensure that testing programs accomplish these goals and remedy barriers to care is essential.

**6. People with HIV/AIDS and other stakeholders must be included in formulating plans for expanded testing.**

Leadership at all levels of government, civil society and the private sector is essential to developing and implementing cogent and effective plans for expanded testing protocols, with measurable goals and objectives, and backed by the commitment of new resources. The call for expanded testing is an opportunity for diverse stakeholders to craft locally and culturally appropriate strategies responsive to community needs. Strategies for reaching people with undiagnosed HIV infection in particular require the input and support of people living with HIV/AIDS, representatives of community-based AIDS organizations, providers and advocates of women's and adolescents' reproductive and sexual health care, public health professionals, clinicians with expertise in working with diverse populations, advocates for patients' rights, healthcare systems administrators and policymakers.

**7. Patients' human rights and informed consent are consistent with, and not opposed to, the goal of expanded HIV testing.**

The importance of patient knowledge, autonomy, and active participation in all aspects of HIV testing and care cannot be overstated. Many current discussions about strategies to expand testing ignore human and civil rights or treat them as barriers to expanded testing and progress in public health policy. Patients' fundamental rights to health care and informed consent are essential to engaging them in testing, prevention, and trusting relationships with primary providers. For people to agree to engage in HIV testing and other activities within the health care system, they must feel secure that their rights to privacy and

confidentiality will not be violated, that they will have access to health care, that they will be able to disclose their HIV status with relative safety, and that they will be able to get work and social services without regard to that status. Public health officials and policy makers must make visible, concrete, credible investments in protections against HIV-related discrimination and must oppose policies and legislation that would marginalize, isolate and/or punish people with HIV and their communities.

**8. Expanded HIV testing must be tailored to different clinical settings, populations, and patient needs.**

Multiple strategies will be needed to appropriately change clinical practices in different settings and to meet the myriad needs of diverse patient populations. Different populations and different individuals present different needs and challenges. By convening ten separate advisory groups, the CDC has implicitly acknowledged that “one size” will not “fit all” in real-world implementation of expanded testing recommendations. In particular, plans to expand the offer of testing in healthcare settings must consider such factors as homelessness, domestic violence, underinsurance, STDs, other disproportionate disease burdens, homophobia, racism, sexism and poverty, all of which affect the extent to which individuals are at risk for undiagnosed HIV infection, as well as the extent to which individuals may face special risks from testing itself. Testing protocols affecting physician-patient communication should reflect the documented, deep mistrust of public health initiatives—particularly screenings and those involving inoculations—still prevalent in African-American and other minority populations. Finally, plans for expanded testing must acknowledge and respond to the inherently coercive nature of certain health care environments (e.g., correctional and other institutional settings) and the need for special procedures with youth and with individuals whose full capacity to consent is compromised or unclear.

**9. Clinicians, medical directors and other providers must receive training and education in delivering high-quality testing programs.**

Medical personnel who do not currently offer HIV testing to their patients must receive intensive outreach and education on changing their clinical behaviors. Public health leaders will need to develop standardized tools and protocols as well as training and technical assistance opportunities to assist these providers. Outreach should be prioritized to those settings likely to identify significant numbers of undiagnosed HIV-positive individuals. All the evidence suggests that combining culturally and linguistically appropriate counseling and respect for patients’ civil and human rights with the offer of an HIV test can substantially increase the number of people who get tested and enter care for HIV.

**10. Clinicians, medical directors and other providers must receive training and education in making appropriate service referrals and linkages to care.**

As the CDC emphasizes in its Recommendations, “[l]inking patients who have received a diagnosis of HIV infection to prevention and care is essential” (p. 6), and “[a]ctive efforts are essential to ensure that HIV-infected patients receive their positive test

results and linkage to clinical care, counseling, support, and prevention services” (p. 10-11). With plans to expand the number of clinicians offering HIV testing, including among non-HIV specialists, public health officials will need to develop concrete plans and guidance to ensure clinicians are able to guide their clients to the appropriate providers for additional HIV prevention and care services they may need. Intensified service referral mechanisms may include expanded online resources, hotlines, and directories as well as expanded promotion of referral and linkage-to-care resources.

**11. Community-based HIV prevention interventions must be expanded in tandem with efforts to expand voluntary HIV testing in healthcare settings.**

Increasing the offer of HIV testing in healthcare settings will miss numerous individuals living with undiagnosed HIV infection. Many individuals will simply not interact with healthcare providers until late in their disease progression, for a variety of reasons. Therefore, planners need to intensify community-based, mobile, and fixed-site HIV testing services; continue to disseminate risk-reduction and testing-promotion messages; and pursue individual and structural interventions designed to help HIV-negative individuals avoid exposure and infection.

**12. Special attention must be paid to the prevention and care needs of at-risk populations.**

Although offering testing regardless of perceived risk may help identify people living with undiagnosed infection, intensive efforts should be made to increase testing and service availability and acceptability in communities with documented higher rates of HIV infection. Better strategies are needed to reduce transmission among disproportionately at-risk populations such as men who have sex with other men (MSM), transgender people, people who trade sex for money and drugs, substance users, and others. Prioritizing increased testing among these populations, combined with effectively linking those testing positive to services and care, is likely to be particularly productive in identifying people living with undiagnosed HIV infection and reducing further transmission.

**13. Expanded testing and the provision of care to all existing and new HIV cases require new and adequate funding.**

HIV testing cannot be significantly expanded without an investment of new funds to plan and implement testing expansion and cover laboratory and staffing costs. Expanded testing cannot be ethically implemented without a corresponding investment of new funds to provide newly diagnosed individuals with care and support services. Existing prevention and care systems already are severely under-funded, leaving large numbers of at-risk individuals and people diagnosed with HIV or AIDS without access to urgently needed care and services. Meeting the needs of the newly diagnosed will simply not be possible without the commitment of significant new financial resources. As the CDC acknowledges in its Recommendations, the primary reason cited by health care providers for not offering HIV testing in hospital emergency departments is “a lack of established mechanisms to ensure

follow-up” (p. 5). Scarcity of resources is not a rationale for failing to expand voluntary HIV testing but rather a reality that must be addressed in the planning and implementation discussion: resources for post-test care must be in place before broadly expanded testing programs are launched, or people will test positive with no place to go for help. Decisions must be made about the most strategic settings to expand testing in order to have the most immediate impact on reaching people with undiagnosed HIV infection in responsible and ethical ways.

#### **14. Testing protocols must address insurance issues.**

As the CDC notes in its Recommendations, one of the barriers to increased testing has been the lack of reimbursement for the cost of HIV screening (p. 4). Getting reimbursement for HIV testing that is ordered when a patient seeks unrelated health care, with no basis in individual risk factors or symptoms, is likely to be problematic, and implementation guidelines should address this issue. In addition, guidelines must be sensitive to the fact that people known to be living with HIV experience stigma and discrimination due both to their HIV status and to the actual or assumed means in which they became infected and therefore patients may not want to have their insurance provider know of their test and their test results.

#### **15. Efforts to assist those with undiagnosed and untreated or unmonitored HIV infection must be evaluated.**

Data collection, analysis, and outcomes evaluation will be needed to measure progress toward established prevention, diagnosis and treatment goals and to better understand the impact of planned expanded testing activities. These efforts need to occur at the local, state, and national levels to continuously improve implementation and inform future activities. Particularly in view of the limited health benefit of testing unconnected to treatment, a central indicator of success must be the number of newly diagnosed individuals who enter and remain in care.

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## Co-Signers

### **ENDORISING ORGANIZATIONS (list in formation)**

AIDS Action Committee of Massachusetts, Inc. (MA)  
AIDS Action Council (Wash., DC)  
AIDS Alabama (AL)  
AIDS Alliance for Children, Youth and Families (Wash., DC)  
AIDS Foundation of Chicago (IL)  
The AIDS Institute (DC)  
AIDS Law Project of Pennsylvania (PA)  
AIDS Legal Council of Chicago (IL)  
AIDS Legal Referral Panel (CA)  
AIDS Network (WI)  
AIDS Project Los Angeles (APLA) (CA)  
AIDS Resource Foundation for Children (NJ)  
AIDS Survival Project (GA)  
AIDS Taskforce of Greater Cleveland (OH)  
AIDS Treatment Activists Coalition (ATAC) (NY)  
Alliance of AIDS Services – Carolina (NC )  
Allies Linked for the Prevention of HIV &AIDS (ID)  
American Civil Liberties Union/Gay Rights and AIDS Projects (ACLU) (NY)  
ACLU of Maryland (MD)  
amFAR, The Foundation for AIDS Research (NY)  
Association of Nurses in AIDS Care (ANAC) (OH)  
Black Gay Men's Leadership Council (PA)  
Better Existence with HIV (BEHIV) (IL)  
Jeffrey M. Birnbaum, M.D., M.P.H., (NY)  
Brother Help Thyself/Health Education Committee (Wash., DC)  
Bronx AIDS Services (NY)  
The Center for HIV Law and Policy (NY)  
Colorado Health Network, Inc. (CO)  
Community HIV/AIDS Mobilization Project (CHAMP) (NY)

Copasetic Women Over 50 (NY)  
The Honorable John Duran, Mayor, City of West Hollywood  
Family Adolescent and Children's Experience Program (FACES), SUNY Downstate Medical Center (NY)  
Federation of Protestant Welfare Agencies (NY)  
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Hispanic AIDS Forum, Inc. (NY)  
HIV/AIDS Law Project (AZ)  
HIV Law Project (NY)  
HIV/AIDS Legal Services Alliance (HALSA) (CA)  
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The Hyacinth AIDS Foundation (NJ)  
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Illinois Caucus for Adolescent Health (IL)  
Institutional Law Project (PA)  
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Lambda Legal (NY)  
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National Association of People With AIDS (NAPWA) (Wash., DC)  
National Gay and Lesbian Task Force, Inc. (Wash., DC)  
National Health Law Program (CA)  
National Minority AIDS Council (NMAC) (Wash., DC)  
New York AIDS Coalition (NYAC) (NY)  
The Night Ministry (IL)

Ohio AIDS Coalition (OH)  
Open Door Metropolitan Community Church (MD)  
The Osborne Association (NY)  
Sarah Patterson, Attorney at Law (OR)  
Pennsylvania Prison Society (PA)  
Planet POZ (NM)  
Planned Parenthood of New York City (NY)  
The Positive Women's Network (PWN)  
Positive Voices (MD)  
Regional AIDS Project (KS)  
Sexuality Information and Education Council of the U.S. (SIECUS) (Wash., DC)  
Sisterhood Mobilized for AIDS/HIV Research & Treatment, Inc. (SMART) (NY)  
Joseph Sonnabend, M.D. (NY, UK)  
South Alabama CARES (Community AIDS Resources, Education & Support) (AL)  
Test Positive Aware Network (TPAN) (IL)  
The Women's Collective (DC)  
Women Organized to Respond to Life-threatening Disease (WORLD) (CA)

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If you would like to join the growing list of organizations and medical professionals who endorse these HIV testing principles, please send the following information to the email address below:

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You will receive an e-mail notifying you when you have been added to the list of signatories.

If you are a medical professional and your organization is for identification purposes only, please let us know.

To join us in endorsing these principles, email [signup@hivtestingprinciples.org](mailto:signup@hivtestingprinciples.org).

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