

OPPORTUNITIES FOR IMPROVING

HIV

DIAGNOSIS, PREVENTION &
ACCESS TO CARE IN THE U.S.

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Community Perspectives on Routine HIV Testing Policies

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Introduction

- Dozens of local, regional, and national organizations have commented on routine HIV testing recommendations
- This presentation summarizes comments and offers personal perspectives on next steps and implementation

Universal Agreement

- HIV testing should be routinely offered
- Reaching people with undiagnosed HIV is a serious challenge
- Too many people learn their diagnosis late in disease
- Expanded care and prevention services must accompany plans to expand testing
- Testing modalities can and must be streamlined
- AIDS stigma, poverty, housing instability, substance use, racism, homophobia, incarceration, domestic violence, and inadequate insurance coverage (among other factors) pose serious challenges to testing acceptance
- Testing alone cannot end the HIV/AIDS crisis

Universal Agreement (cont'd)

Testing must be

- Available, accessible, highly reliable, and confidential
- Voluntary and free of coercion
- Provided with informed consent so that test subjects understand
 - nature of test
 - what test results mean
 - implications of a positive result
- Provided in settings where counseling and prevention education are delivered or made readily available
- Provided with needed service referrals and linkages

AIDS Advocates Overwhelmingly Believe

- Pre-test counseling is valuable, especially for high-risk negatives
- Written, informed consent is valuable, achievable, and an important activity to ensure individuals fully understand their decisions and are protected from medical abuses
- Written, informed consent is not cumbersome, time prohibitive, or an impediment to testing acceptance

Critical Concerns

- Verbal or combined consents: can they be fully informed?
- Will test subjects be informed of the voluntary nature of HIV testing and afforded a chance to decline without penalty?
- How will expansion of routine opt-out testing and accompanying care needs be financed?
- How will expansion of routine opt-out testing affect the availability of other needed prevention services?
- Which settings and populations are best suited for opt-out testing; which are not?
- Will providers receive adequate training and assistance to ethically and responsibly implement routine opt-out testing?

Critical Concerns (cont'd)

- How will implementation be monitored?
- How will ethical abuses in HIV testing be prevented?
- How will success or failure of routine opt-out testing expansion be measured?
- What are the implications of routine opt-out testing on high-risk negatives?
- What care and prevention services will newly identified positives need?
- How will newly diagnosed people gain access to (and maintain) high-quality care and other essential services?
- How will CDC guide state policy development?

Critical Concerns (cont'd)

- How will calls for routine opt-out testing affect state and local confidentiality protections for HIV-positive people?
- How will routine opt-out testing affect levels of HIV misinformation?
- How many cases of undiagnosed HIV can be identified and linked to care through routine opt-out testing?

Selected Comments

- **NAPWA:** “While 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.”
- **NBLCA:** “Counseling 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.”

NAPWA = National Association of People With AIDS

NBLCA = National Black Leadership Commission on AIDS

Select Comments

Joint statement

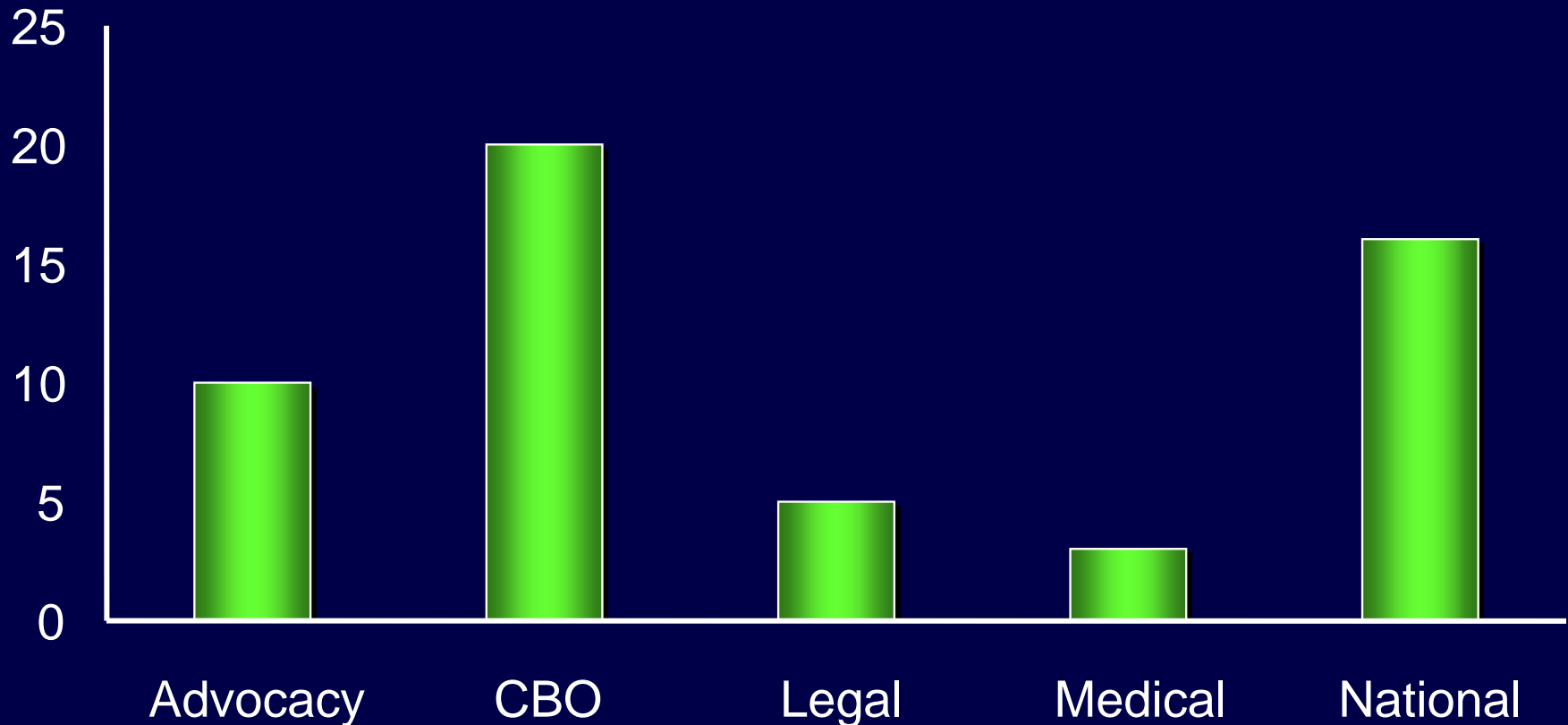
“De-linking counseling from testing is highly problematic for many vulnerable populations. For example, adolescents and young people, who are at particularly high risk of stigma and rejection from family and friends when disclosing their HIV status and who are often dependent on adults to access health 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.”

Select Comments

Housing Works

“Do New York laws that require simple written consent for HIV testing and an explanation of HIV risk factors prevent large-scale HIV testing? Apparently not. New York City public hospitals dramatically increased voluntary HIV testing — with standard written consent — this year and found more than twice as many HIV-infected patients than in 2005.”

Diverse Organizations Oppose Changes to Written, Informed Consent and Counseling Joint Statement Endorsers



n=54

Joint comments submitted on March 31, 2006

<http://www.champnetwork.org/media/Testing-Letter.pdf>

Personal Perspectives

- HIV screening is nowhere near analogous to cholesterol screening
- The uninsured and other vulnerable populations are unlikely to benefit from routine opt-out testing
- Eliminating pre-test counseling is inconsistent with other federal HIV initiatives
- CDC recommendations are fueling a dangerous debate about mandated testing policies

Advocacy Perspectives

“Data show most people offered testing accept it ... We should not be doing this on the cheap.”

Congresswoman Donna Christian-Christiansen, MD (D-VI) at AIDS 2006 on proposed mandated testing for prisoners and pregnant women

- **At no point** must we accept or condone lower quality or substandard testing services
- Routine opt-out testing **will not** replace the need for a robust prevention and care agenda

Advocacy Perspectives

“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.”

Mark McLaurin, executive director, New York State Black Gay Network
On the October 2006 CHAMP community conference call

Several Pilots Show HIV Testing in the ED is Possible

If ...

- Management supports and champions it
- Training and support for ED personnel is provided
- Funding is identified for test kits, counseling, and linkage/referral/follow-up costs
- Confidentiality can be assured
- Procedures are established to obtain informed consent, provide HIV information and make care linkages and referrals for those testing HIV-positive

Examples of Logistical and Capacity Challenges

- Cook County Hospital ER sees over 200,000 patients each year. Testing each for HIV would cost more than \$3 million for test kits alone, not including staff
- Chicago Department of Public Health STD clinics report having an estimated 200 turn-aways a month
- Heart of Illinois AIDS Clinic in Peoria tested 36% more HIV-positive people in the first 9 months of 2006 than in all of 2005 — clinic officials report no capacity to provide more testing and care services

In Every State, Testing Expansion is Entirely Possible Without Amending a Single Law

New York City Public Hospitals

- Increased number of people tested in 2006 by 63%
- Found more than double the number of HIV-positive people than in 2005

How?

- Use of a simple, one-page written consent and HIV testing explanation form
- Rapid HIV testing
- Streamlined written consent
- No state or local law-change required

Consider Illinois: A Case Study in Testing Expansion

- Increased testing among all pregnant women and newborns from 73% in 2005 to **greater than 99%** in 2006

How?

- Established an HIV perinatal hotline for L&D clinicians to provide medical and social service linkages
- Deployed HIV specialists to train 15,000 L&D and nursery staff in the state's 133 birthing hospitals
- Training topics: conducting HIV counseling, obtaining written informed consent, rapid testing, prophylactic care, and follow-up
- State developed and disseminated standardized and streamlined counseling and consent materials
- Public health collects monthly reports from L&D on HIV testing

Implementing Testing Expansion

- One size **does not** fit all: we must pursue locally appropriate strategies
- We must stay focused on the goal of **reaching those with undiagnosed HIV infection**
 - Opt-out is a means to an end but not an end in itself
- If testing is to be expanded or become universally offered, new models and resources will be needed to support **linkage to care**
- Implementation will require careful planning, stakeholder involvement, sensitivity to local systems, and targeted work to meet incremental goals

Local and National Strategies To Expand Testing Must

- Include strong research and evaluation components
- Identify priority populations/settings
- Leverage increased prevention and care funding
- Expand early intervention service models
- Target training and educational resources directly to clinical settings
- Improve HIV knowledge among physicians
- Increase HIV testing in STD settings
- Educate policymakers and the media about the multifaceted responses, including testing, that are needed to halt the epidemic

Call to Action

AIDS-related meetings risk becoming little more than “glorified talk-shops” unless they catalyze actions to move forward

AIDS 2006 Plenary Speaker Mark Heywood of South Africa

Before this meeting concludes ...

We should:

- **Pen a joint statement** supporting increased care and prevention funding as pivotal to efforts to identify and assist people with undiagnosed HIV infection
- As a group determine to lobby forcefully for early interventions (Title III), case management, and other essential services
- Urge Congress to adopt the Institute of Medicine's 2004 recommendations on public financing and the delivery of HIV/AIDS care
- Urge CDC to invest in training and technical assistance for medical providers and within clinical settings—whether they adopt routine opt-out or not
- Advocate for a strong research and evaluation component to track progress and guard against abuses
- Articulate the centrality of strong patient protections and confidentiality provisions for wider acceptance of HIV testing and care services

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- Housing Works, *HIV Testing & Treatment What's Really Broken?* (10/06/2006), http://www.hwadvocacy.com/update/archives/2006/10/hiv_testing_tre.html
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