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Issues at a Glance

HIV Vaccine Research: Creating Support Among Communities of Color*

HIV preventive vaccines are part of a global response to the HIV and AIDS epidemic—a global response that also includes: education; efforts to encourage people to modify or avoid risky behaviors; drug abuse treatment; needle exchange programs; testing and treatment of sexually transmitted infections other than HIV; efforts to prevent mother-to-child transmission; and treatment with anti-retroviral drugs. A successful preventive vaccine candidate can add a powerful new tool in the fight to prevent HIV. Moreover, a successful preventive vaccine may be our best hope for ending the epidemic among communities of color across the United States.

Worldwide since 1983, 20 million lives have been lost to HIV, the virus that causes AIDS.[1] Moreover, HIV infection rates continue to rise, despite current advances in the prevention and treatment of HIV and AIDS.

- Experts estimate that more than 38 million people across the globe now live with HIV or AIDS and that as many as 16,000 new HIV infections occur each day.[1,2]
- Experts estimate that as many as 950,000 people in the United States live with HIV or AIDS;[3] at least half are under the age of 25.[4]
- Through 2001, African Americans and Latinas accounted for 84 percent of cumulative AIDS cases among women ages 13 to 19, and 78 percent of cases among women ages 20 to 24.[5]
- Through 2001, African Americans and Latinos accounted for 62 percent of cumulative AIDS cases among men ages 13 to 19 and 60 percent of cases among men ages 20 to 24.[5]
- Of HIV infection cases reported in 2001 among men ages 13 to 19, 46 percent occurred in young men who have sex with men (YMSM); among men age 20 to 24, 49 percent occurred in YMSM.[5]

A safe, effective, and affordable HIV vaccine offers the best long-term hope for controlling the HIV and AIDS pandemic.

Communities of Color—Underrepresented in HIV Vaccine Trials

Communities of color are disproportionately infected with HIV and are also disproportionately affected by the HIV and AIDS pandemic. Yet relatively few people of color in the United States volunteer for HIV prevention vaccine trials. The lack of diversity among volunteers for HIV prevention vaccine trials may have a serious impact on communities of color and on the discovery of a prevention vaccine effective for *all* populations. This is important because the U.S. Food & Drug Administration (FDA) may approve a vaccine only for use in the communities and populations among which it has been tested. By not participating in HIV prevention vaccine trials in large enough numbers, people of color may be unable to receive a vaccine, if and when one is found to be effective with other populations.

Barriers to the Participation of People of Color

The research community identifies several challenges to full participation in vaccine trials by members of communities of color. The best way to overcome these barriers is for interested and caring people within affected communities to address the barriers directly, both with other members of their community and with researchers. Barriers include the following:

Barrier #1, Myths, misconceptions, and misinformation about HIV and AIDS[2]—Myths and misconceptions abound even though great deal of accurate information regarding HIV and AIDS is now available in the languages, idiom, and cultural context of African Americans and blacks, Hispanics and Latinos, many Native American and Alaska Native cultures, and a variety of Asian and Pacific Islander cultures.

* Throughout this brief, communities of color include: African Americans and/or blacks; Asian and Pacific Islanders (API); Latinos and/or Hispanics; and Native Americans, American Indians, and/or Alaska natives.

Barrier #2, Distrust of government and belief that a cure or vaccine for HIV already exists[2]—According to a recent survey, 48 percent of African Americans and 28 percent of Hispanics believe that an HIV vaccine already exists and is being kept secret by the government; 20 percent of all American adults believe this.[2] One legacy of the infamous Tuskegee syphilis study is a widespread fear in communities of color that HIV is a government-originated illness, designed to kill people of color.[6] The sad truth is that this fear may prevent people of color from taking important HIV prevention steps, such as using condoms and/or participating in vaccine trials.

Barrier #3, Homophobia and HIV discrimination[7]—Homophobia fuels the epidemic by provoking sexual risk-taking among heterosexual individuals and among gay, lesbian, bisexual, and transgender people. At the base of these attitudes is fear—fear of being thought gay, fear of being targeted for violence, and/or fear of being thought to be HIV-infected. Discrimination against those infected with HIV or living with AIDS also fuels the epidemic by preventing infected people from being open about their condition and/or seeking treatment.[7]

Barrier #4, Lack of openness about sexuality—Research shows that an unwillingness to talk about sexuality and sexual health issues can leave young people unprepared to protect themselves when they initiate sex and can lead to a lack of open and honest conversations between partners about their sexual history and their need for protection.[8,9]

Barrier #5, Fear that HIV prevention vaccines may cause HIV infection[2]—This fear probably springs from a misunderstanding about vaccines. People do not understand that trial vaccines are man-made, contain *no* HIV, and *cannot* cause HIV infection. Vaccine trial volunteers may test positive for HIV antibodies *because the vaccine properly triggers the immune system to fight HIV*.

Barrier #6, Cultural beliefs—Different cultures approach topics such as illness and relationships in very different ways. For example, at least one Native American culture teaches that speaking about an illness will bring it into existence. Thus, it is important to approach subjects such as HIV prevention and HIV vaccines in a careful manner that respects and recognizes cultural traditions.[10]

Barrier #7, Language—People whose first language is not English can have difficulty finding accurate and understandable information about HIV and AIDS and about HIV vaccine trials. They may experience difficulty in communicating with health care workers, and they may be unable to give informed consent, if vaccine trial information is not readily available in their own language.[11]

Barrier #8, Past encounters with racial/ethnic discrimination—If potential volunteers have encountered discrimination or lack of cultural sensitivity on the part of health care workers in the past, they may be reluctant to expose themselves to further insult.[10]

The Facts—Understanding HIV Vaccine Research

Currently there is no cure for HIV or AIDS, nor is there a preventive vaccine. Scientists are conducting clinical trials to develop HIV preventive vaccines. A ***preventive HIV vaccine*** is a substance that will teach the body's immune system to recognize and protect itself against HIV.

- ***Preventive HIV vaccine candidates are of man-made materials that CANNOT cause HIV because they do not contain HIV.*** Scientists believe that an effective HIV prevention vaccine, given before exposure to HIV, could have several outcomes, including:
  - Preventing infection in most people;
  - Preventing infection in some people;
  - Preparing people's immune system to block *continued* infection and to eliminate the virus (vaccines against measles, mumps and polio work this way); and/or
  - Delaying or preventing the onset of HIV-related illness (AIDS).[12]
- ***Because the vaccine is meant to cause the body to produce antibodies against HIV, a volunteer may test positive after receiving the vaccine for HIV antibodies.*** Testing positive for antibodies does ***not*** mean the person is infected with HIV. It means the vaccine candidate worked as intended, to encourage the body to fight off HIV. Preventive vaccines *cannot* cause HIV infection.[12]
- ***Six to eight years may be needed for an HIV prevention vaccine candidate to progress through required clinical trial phases before the Food and Drug Administration (FDA) would consider its approval for public use.*** The three phases of preventive HIV vaccine clinical trials are:
  - **Phase I** involves a small number of healthy, HIV-negative volunteers. This phase tests the safety and various doses of the vaccine; the phase usually lasts 12 to 18 months.
  - **Phase II** involves hundreds of healthy, HIV-negative volunteers. This phase tests the safety and immune response triggered by the vaccine and can last up to two years.

- **Phase III** involves thousands of healthy, HIV-negative volunteers. This phase tests the safety and effectiveness of the vaccine and can last three to four years.[12]

- ***Today, ordinary people around the world play a vital role as volunteers in HIV vaccine research.*** Without the thousands of people who have volunteered or are currently volunteering, finding an effective vaccine would be impossible.[12]

- ***Prior to participation in a vaccine trial, volunteers are fully informed about the process, the vaccine(s) being tested, and possible outcomes.*** Volunteers who still wish to participate then give "informed consent," officially agreeing to take part in the trial. Once enrolled, a volunteer may quit a trial at any time.[12]

- ***Only healthy, HIV-negative men and women between the ages of 18 and 40 may volunteer to participate in a vaccine trial.*** They must also be able to understand the potential risks and benefits of participation.[12] Currently, people under age 18 may not participate in vaccine trials, although this may change in coming years.

- ***Throughout their participation, volunteers receive counseling on avoiding behaviors that can put them at risk for HIV infection.*** Volunteers learn that, if they engage in HIV-risk behaviors, they may become infected with HIV, despite their participation in the vaccine trial. Volunteers may always ask for testing at the trial site to determine whether their sexual or other risk behavior has resulted in HIV infection.[12]

- ***Scientists from across the world—in public and private research organizations—are working to make an HIV vaccine a reality***. Research organizations include universities, biotechnology companies, pharmaceutical firms, and government agencies. Scientists' goal in this research is to find effective ways to prevent HIV.[12]

- ***Researchers are separately evaluating therapeutic HIV vaccines—vaccines that will help people already living with HIV infection or AIDS.*** Researchers know that what works to prevent HIV infection may not necessarily work to treat people who are already infected with HIV; and what works to mitigate the effects of HIV infection may not work to prevent HIV.[12]

- ***NIAID's HIV Vaccine Trials Network (HVTN) is one of the largest organizations conducting HIV vaccine research trials in the United States.*** Since 1987, NIAID* has funded the testing of many HIV preventive vaccine candidates in the United States and around the world. HVTN currently has trial sites in Boston, Massachusetts; Providence, Rhode Island; Rochester, New York; New York, New York; Baltimore, Maryland; Nashville, Tennessee; Birmingham, Alabama; St. Louis, Missouri; San Francisco, California; and Seattle, Washington. Over 20 vaccine candidates are currently in various trial phases in the United States and more than 30 are in various trial phases in Africa, Asia, the Caribbean, and South America. Many more vaccines will begin testing in the next two years.[13]

Community Support and Participation—Overcoming the Barriers

The barriers that inhibit people of color from participating in HIV vaccine trials underscore several needs. Communities of color need accurate, understandable, and culturally appropriate information about current efforts to develop HIV prevention and HIV therapeutic vaccines. Researchers need to build trust within communities of color, because trust is critical to their full participation in vaccine trials. Building trust will require that: scientists and researchers are visible within the community; research teams include members of the concerned communities; and researchers build cultural sensitivity and awareness. These actions may help lessen feelings of vulnerability and increase trust between researchers and communities of color.

Involving Youth of Color in Vaccine Trials

Since almost half of all new HIV infections occur among youth under age 25, and since rates of HIV infection are disproportionately high among youth of color,[4,5] young people in communities of color remain at high risk for HIV infection. With each day that passes, more young people are infected with HIV. Thus, it is crucial that youth ages 18 through 24 participate in HIV vaccine trials. Especially crucial is the participation of youth of color and of young men of color who have sex with men. A successful HIV prevention vaccine trial requires thousands of participants, male and female, from varied ethnic backgrounds, to ensure the vaccine's effectiveness in all populations. And, it is absolutely essential that the vaccine—when found—is also certified for use in teens and young adults.

In addition to becoming trial volunteers, youth in communities of color can show support for HIV vaccine research by:

- Letting others know of their support for HIV vaccine research;
- Providing education about HIV and the critical need for an HIV prevention vaccine;
- Dispelling myths and sharing accurate information about HIV and AIDS and about vaccine research; and
- Supporting a family member or friend who is a volunteer.

* National Institute for Allergy & Infectious Diseases, a part of the National Institutes of Health

Resources on HIV Vaccine Research

- **Advocates for Youth**, www.advocatesforyouth.org
- **AIDSInfo**, Overview of Vaccines, www.aidsinfo.nih.gov/vaccines
- **HIV Vaccine Trial Network**, www.hvtn.org
- **National Institutes of Health**, Vaccine Research Center, www.vrc.nih.gov/VRC

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11 Davis L. *Adolescent Sexual Health & the Dynamics of Oppression: A Call for Cultural Competency* [Issues at a Glance] Washington, DC: Advocates for Youth, 2003.

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13 NIAID. *HIV Vaccine Awareness Day* [Fact Sheet]. Rockville, MD: NIAID, 2004.

Written by Nahnahsha Deas, Program Associate, HIV/STI Prevention Programs

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2000 M Street, NW, Suite 750 • Washington, DC 20036 USA • Phone: 202.419.3420 • Fax: 202.419.1448 • www.advocatesforyouth.org