

HEARING THEIR VOICES

A QUALITATIVE RESEARCH STUDY ON
HIV TESTING AND HIGHER-RISK TEENS

PREPARED BY
MICHAELS OPINION RESEARCH
FOR THE HENRY J. KAISER
FAMILY FOUNDATION

THE HENRY J.
KAISER
FAMILY
FOUNDATION

CONTENTS

ACKNOWLEDGEMENTS..... 1

EXECUTIVE SUMMARY:

Overview 2

Summary of Findings..... 4

METHODOLOGY..... 10

DETAILED FINDINGS:

Chapter One: Barriers to HIV Testing..... 12

Chapter Two: Testing Motivators..... 23

Chapter Three: HIV Testing Experiences..... 31

ACKNOWLEDGMENTS

The researchers wish to express their appreciation to the following agencies and individuals who provided expert input for this study, actively recruited participants, allowed access to their facilities and without whose assistance this research would not have been possible:

Dr. Robert Johnson, Walter Douglas and James E. Anderson, Jr., Division of Adolescent & Young Adult Medicine, New Jersey Medical School, Newark; Dr. Peggy Smith and Ruth Buzi, Teen Clinic, Ben Taub Hospital, Houston; Chris Ambrose and Liza Brown, The Door, New York; Kevin Magruder and Michael Saunders, Gay Men of African Descent, New York; Edwin Ortiz and Rose Santiago, Youth Against Alcohol and Drugs, Bronx, NY; Dr. Donna Futterman, Montefiore Medical Center, Bronx, NY; Mario Cooper, Leading for Life, New York; Dr. Reynald Jean and Kira Villamizar, Miami-Dade Department of Health; Lorraine Pall, R.N., and John Kiriakon, Division of Adolescent Medicine, University of Miami; Carl Strange, Hetrick-Martin Institute, New York; Janet Shalwitz, San Francisco Department of Public Health; Vera Davis and Ken Baines, Covenant House, Houston; Michael Roy, Streetwise, Houston; Michelle Paul, Arbor House, Houston; Leslie Reed, Planned Parenthood of Middle Tennessee, Nashville; Mary Jo Johnson, Chase-Brexton Health Services, Baltimore; Jim Mitchell, Community AIDS Resources, Miami; Sandra Odusanya, Lock Town Community Mental Health, Miami.

EXECUTIVE SUMMARY

OVERVIEW

The portrait of the AIDS epidemic in the U.S. has changed. AIDS is increasingly a disease of the young and the epidemic is shifting further towards African-American and Latino youth. Teenagers, especially young women and men in disadvantaged urban communities of color, are poised to become the tragic new face of AIDS in the United States.

The U.S. Centers for Disease Control and Prevention (CDC) estimates that as many as *two-thirds* of STD cases¹ and *half* of all new HIV infections are among young men and women under age 25, the majority of whom are infected through sexual transmission.²

Moreover, recent data from the CDC indicate that approximately one-half (51%) of new AIDS cases among 13- to 19-year-olds are among women.³ A recent study of 25 states found that African-Americans account for two-thirds (63%) of HIV infections among 13- to 24-year-olds.⁴ The CDC also notes that although the incidence of AIDS cases overall is declining, “there has *not* been a comparable decline in the number of newly diagnosed HIV cases among young people” in these states.

National surveys conducted by The Henry J. Kaiser Family Foundation have found that young people are indeed very concerned about HIV. Overall, four in ten teens aged 15 to 17 (44%) say HIV/AIDS is among the *most* important health issues facing teens today⁵ and teens express high rates of personal concern about becoming infected with HIV (32% say they are “very concerned” and 22% say they are “somewhat concerned”).⁶

Despite their concern, however, sexually active teens under age 18 are far less likely than their adult counterparts aged 18 to 44 to have been HIV tested (25% to 59% respectively).⁷ Background research by The Kaiser Family Foundation has highlighted a gap in HIV testing availability for teens, especially higher-risk teens. By higher-risk we mean sexually active and economically or socially marginalized youth living in urban areas with relatively high rates of AIDS diagnoses and, by extension, HIV infection.

HIV testing is a critical tool in the continuum of HIV prevention and treatment. The development of effective treatments for HIV has led to a new emphasis on the importance of testing and early care for those who are infected. In addition, knowledge of one's HIV status is an important part of preventing the spread of HIV. Despite the need, most HIV-prevention campaigns focus on safer sexual behavior. Few major efforts for youth focus on the need for testing and early care.

This study was commissioned by The Henry J. Kaiser Family Foundation in an effort to learn more about young people's issues, concerns and attitudes toward HIV testing. The findings presented in this report are the result of a series of confidential, in-depth personal interviews and focus group sessions conducted in four AIDS epicenter cities with 73 higher-risk teenagers, including those who have been HIV tested and those who have not. In addition, a focus group was conducted with healthcare professionals, youth advocates, and HIV counselors. Interviews were conducted in February and March, 1999. These findings provide insight into the often complex issues that surround young people's perceptions of and experiences with HIV testing and their reasons for seeking and not seeking testing.

It is important to note that the findings of qualitative research such as this are not intended to report attitudes and experiences as statistical data. Rather, the research reveals patterns of feelings and emotions that underlie teens' otherwise quantifiable behavior or knowledge about HIV testing. These interviews are highly qualitative by design and elicit information about factors that may influence or be indicative of attitudes or behavior. It cannot be assumed that the information revealed is either definitive or representative of the population as a whole.

SUMMARY OF FINDINGS

This report presents the perceptions, attitudes and experiences of higher-risk teenagers toward HIV testing in intimate and often poignant detail. As teens describe their fears and painful transgressions relating to sexual experiences with others, we are provided with considerable insight into the lives of inner-city youth and the challenges they face as they transition from childhood to adulthood.

While teenagers today know gay men are one of the higher risk groups for contracting HIV, they do not perceive HIV to be a gay disease. In fact, most of the teens interviewed knew someone in their neighborhoods who was HIV-positive or who had died from AIDS, and some had immediate family members who were infected or who had died. Still, none of those interviewed seemed to connect the dots between infection rates in their communities and their own risks. While HIV prevention information is clearly reaching young people, virtually all teens, with the exception of those in New York, seemed surprised that their cities had some of the highest rates of infection in the country. Young people generally believe IV drug use and sex with users are the behaviors that put one at risk for HIV. Moreover, for most of these teens, their sense of risk is further diminished because they do not personally know anyone *their age* who is HIV-positive.

Whatever their sex, sexual orientation, race or ethnicity, these young people share a struggle to find affection, intimacy or sexual satisfaction in the arms of another. Some want desperately to be loved, so much so that they will knowingly disregard what they've been taught in school and put themselves at risk for HIV and other sexually transmitted diseases (STDs). Other teenagers are merely seeking sexual experiences, not serious relationships. In their sexual pursuits, these teenagers never intend to cause harm to others; they are all just unaware of how HIV can enter their world with the slip [off] of a condom. With frightening frequency, nearly all the teens we interviewed reported having had unprotected sex.

In fact, this research discovered troubling attitudes among teenagers toward condom use. Most of the teens we interviewed admitted having had unprotected sex, including some of those who were sex workers, IV drug users, or who have a parent or sibling who is HIV-positive, or a relative who has died from AIDS.

Moreover, teens believe they have acted “responsibly” and are not at risk for HIV because they “go bare” only with someone they “trust” or if their partners are “clean,” they use condoms “most of the time” or they “only used clean needles.”

Teens recognize that condoms provide protection from HIV and other STDs. But for well over a decade, HIV prevention education has used the words “protection” and “condom use” synonymously and the underlying rationale for condom use presumes that people feel the need to be “protected” from their partners, a presumption that does not seem to hold with teens.

Consequently, without a sense of being at risk, there is no strong perceived need for HIV testing. And despite whatever doubts and emotional turmoil HIV tested teens may experience while waiting for HIV test results, most of them say that somewhere, way down deep, they were confident their test results would be negative.

Nevertheless, concerns about potential exposure to HIV underlie most teens’ decisions to be HIV tested. Knowledge of unsafe sex lurks in their consciousness and anxiety begins when they break up with a lover or hear rumors about a partner’s cheating or risky sexual behavior. The voice inside their heads starts chanting the HIV prevention education mantra, “anyone could get HIV.” In this state of mind, should opportunities to be tested arise, most teens will accept the challenge; perhaps more than anything, HIV testing is seen as an opportunity for peace of mind.

When HIV tested teens were asked what emotions they experienced upon hearing their test results, most exclaimed “Relief!” Then, as if being sworn in for testimony, they held up their hands and told us, “I made a promise to myself” never again to have sex without a condom. When asked how long that promise lasted, some young people confessed “not long;” one young man said, “I think I broke my promise the next day.”

PROFESSIONAL PERSPECTIVES

Our focus group with healthcare professionals highlighted important issues for our research. Although these professionals agreed that some groups of teenagers are at higher risk for HIV, they frequently commented that class distinctions, education and race are not determinants of who is at risk for HIV, who will test positive or who is having

unprotected sex. One professional insisted that “the risk is unprotected sex, period!” and another noted that half of the young women who test positive at her facility do not fit the high risk profile.

Other professionals felt a neighborhood-by-neighborhood strategy is the only effective way to reach teens who are at the highest risk for HIV. Several professionals also noted a strong correlation between high positive rates and teens with mental illness or teens with histories of sexual abuse.

Professionals articulated a wide range of factors they believe are motivating and deterring youth from being HIV tested. In fact their perceptions of factors that motivate teens to get tested parallel actual reports from the teens we interviewed. Professionals and teens disagreed, however, over the degree to which teens are comfortable being tested in groups and over their willingness to share with peers personal health information, especially STD diagnoses or HIV testing. Some professionals asserted that teens attach little stigma to having an STD, that an STD might even be considered a “badge of pride” or “rite of passage.” In interviews, however, teens were clearly appalled at such a notion. They say STDs label teens as being “not clean” and that having HIV means rejection and isolation.

KEY MOTIVATORS AND DETERRENTS

Overall, interviews with both teens and professionals suggest that the key factors motivating HIV testing among teens include:

- *Fear of exposure to HIV*
- *Experiencing symptoms of STDs*
- *Recommendations of health professionals, parents, partners and select peers*
- *Access to confidential, convenient and caring youth healthcare centers; “teen friendly” test sites*

In contrast, factors detected as pivotal in deterring HIV testing among teenagers include:

- *Internalized beliefs that they are outside the specter of risk*
- *Lack of awareness about HIV infection rates in their communities*
- *Fear of being labeled and stigmatized by their families, friends and communities*
- *Perceptions of the consequences of living with HIV*
- *Lack of knowledge about the location of “teen friendly” testing facilities*

- *Healthcare visits that are only symptom-driven; the lack of routine health exams*
- *The psychological hurdle of admitting mistakes and “incorrect” behavior*

ACCESS AND ENCOURAGEMENT ARE KEY

Overall, young women generally expressed a heightened desire to discuss sexual issues with physicians, while young men were clearly not comfortable with this topic. Furthermore, unless they need physicals to play sports at school or they are sick, young men reported that they rarely see a doctor. Most teens say they go to public clinics for their medical needs and their impressions of the people working in these places have a strong bearing on whether they follow professional advice and return for follow-up care.

The more teen-focused the facility, the more likely teens were to trust the individuals working there. Most importantly, while some teens say doctors' recommendations to be HIV tested made them “very nervous,” they nonetheless appear very responsive to such advice from physicians and other health professionals.

According to the professionals interviewed, visits by teens to healthcare facilities are frequently motivated by symptoms of sexually transmitted diseases; this was true for some of the teens who participated in this study. These professionals also indicated that an effective way to reach teens for HIV testing would be to provide free STD testing. The research supports this viewpoint as well, as many teens indicated that their HIV tests were recommended with and incorporated into a series of other tests. Some of these professionals also suggested that most teens do not recognize the connection between STDs and being at higher risk for HIV. Although the responses of several teens did reflect that perception, most teens we interviewed seemed aware of the relationship between STDs and HIV.

RISK ASSESSMENT SCREENERS

The professionals who were interviewed for this study added that screener questionnaires are routinely administered to identify teens who are at higher risk for HIV and other STDs. When teens exhibit higher risk behavior, HIV testing is encouraged. None of the young women had a strong issue with questions about sexual activity, unless they came from a physician that knew their mother. As one 15-year-old Latina explained it, “The doctor asked me questions like, ‘Are you sexually active?’ And I said, ‘No.’ I’m a little nervous, she knows my whole family....She would probably look at me differently.”

In contrast, young men complained that the battery of questions they were asked was “too personal.” Gay youth in particular felt they were being treated differently than other teens because of these questions. “When you tell them you’re gay, they put down that one clipboard and pick up another one.” Another gay youth observed, “They put the rubber gloves on. Real quick.”

TEEN-FRIENDLY SITES

The research suggests that multiple conditions constitute “teen-friendly” testing facilities. When these conditions are present, teens are motivated to be tested; when absent, they deter or impede HIV testing. Professionals repeatedly stressed that “teens need to feel safe” at the facilities they visit for health services and that in a safe environment they are more likely to agree to HIV testing when encouraged by health professionals. The opinions expressed by teenagers strongly confirm this view.

Overall, “teen friendly” facilities are those that provide:

- *“Respect” for teens who are sexually-active*
- *Free testing*
- *A “medical” environment*
- *A broad range of teen health services*
- *Confidentiality*
- *Options for oral or blood-drawn HIV testing*
- *Convenient access to public transportation or locations within walking distance to schools*
- *Fewer questions and paperwork*

Some youth who have not been tested for HIV say that if they decide to be tested, they would probably locate a testing site by relying on the Yellow Pages or recommendations from friends. If their experience at a clinic is negative, teens say they will simply walk out or won't go back. Of critical importance to sexually active young people is receiving respect from healthcare workers, an acknowledgment that being sexually active does not make them less deserving of common courtesy.

When one 16-year-old Latina who has been HIV tested more than once was asked how she benefited from HIV testing, she summed up her feelings this way:

A sense of pride. I think young adults that have sex, that's something we're stripped of, pride. 'Cause they have those commercials [about abstinence], "Oh, not me. Not now. I'm not ready, because I'm better." I mean, are we not better because we chose to have sex at a young age? I don't understand that. Am I not going to, you know, be successful and work in an office in Manhattan because I have sex? They act like sex is just like, "That's it, you're doomed for hell. You're going to be on drugs and on the welfare line." So you know, I think, just by somebody going to get that AIDS test and taking birth control and all that, you get a sense of pride that I feel like a lot of people took away from us.

METHODOLOGY

To satisfy the research objectives, we designed a study employing both a series of focus group sessions and private one-on-one interviews with teens in four of the top 10 cities having the highest incidence of AIDS cases among those aged 13 to 25: Miami, Houston, New York and Newark, N.J.

- Private, in-depth interviews lasting 45 minutes to one hour were utilized to increase the likelihood of candor in discussions about deeply personal sexual attitudes and behavior, particularly with regard to behavior that may be perceived as “incorrect.” Interviews were conducted both with teens who have been HIV tested and with those who have not been tested.
- In addition, focus group sessions, each lasting approximately 90 minutes, were conducted with HIV tested teens segregated by sex and segmented by key demographic groups to enhance the opportunity for discussion about common cultural experiences and peer attitudes that might influence HIV testing decisions.

Prior to conducting these interviews, we convened a telephonic focus group session with and sought input from a select group of eight healthcare professionals, youth advocates and HIV counselors from six major urban areas who have direct personal experience with adolescents on issues related to HIV education, prevention, testing and care. This session served to identify issues for further investigation, informing the development of the discussion and moderator’s guides used during the subsequent interviews and focus group sessions with teens.

All of the professionals participating in the discussion group represented agencies that conduct HIV testing with young adults and teenagers, although some reported being “new” to providing HIV health and counseling services to teens.

Most professionals worked for agencies serving lower socioeconomic and minority populations and two represented agencies with particular expertise in providing services to gay and lesbian youth. The teenagers who were interviewed represented the populations served by these agencies.

In-depth interviews and focus group sessions with teens were conducted at professional research facilities, as well as on-site at several teen clinics and youth service agencies. In reaching targeted youth to participate in these sessions we collaborated

with dozens of community-based youth service organizations and clinics, including teen homeless and runaway shelters, substance abuse centers, HIV outreach and counseling programs, teen health and pregnancy clinics and juvenile justice counseling agencies.

Potential participants were screened prior to interviewing using a questionnaire developed to identify those with high HIV risk factors and to assure a mix of participants by targeted age, sex, socio-economic, racial and ethnic characteristics. Brief post-interview questionnaires were also administered to gather additional demographic and behavioral information.

Recruited participants were all sexually active teens, aged 15 to 19, who have had multiple sexual partners, and included those with histories of sexually transmitted diseases, IV drug use, substance abuse problems and exchanging sex for money or drugs. Of the 43 young men and 30 young women participating in private interviews and focus group sessions, 50 had been HIV tested and 23 had not been tested; 37 were African-American, 33 of Latino descent and three white. The vast majority of those interviewed were heterosexual, while 14 self-identified as gay, lesbian or bisexual.

To maintain focus and ensure consistency, only two female researchers with extensive experience conducting interviews on sensitive subjects with adolescents conducted the interviews for this project. The research was designed by Maureen Michaels, president of Michaels Opinion Research, Inc., a New York City-based public opinion research firm, and by The Henry J. Kaiser Family Foundation. The research staff on the project included Ms. Michaels, Bruce Carlson, Cindy Boatwright Mulder and Sarah Lightdale.

DETAILED FINDINGS

CHAPTER ONE: BARRIERS TO HIV TESTING

Interviews conducted with teenagers, both those who have been HIV tested and those who have not, reveal a number of different factors that are impacting young people's perceived need for and decisions about HIV testing. The strongest barriers to HIV testing appear to relate to internalized perceptions of risk and attitudes about the impact of HIV on one's physical and emotional well-being. Other key obstacles relate to the availability and accessibility of healthcare services geared specifically for teenagers.

Overall, the research suggests that the major deterrents to HIV testing among teens include:

- ***Internalized exclusion from and misperceptions of risk that result from teens':***
 - ▶ Regular, but admittedly inconsistent, safer sex behavior.
 - ▶ Convictions that they are "not promiscuous."
 - ▶ Confidence that they are involved in monogamous relationships.
 - ▶ Belief or knowledge that a partner has been HIV tested.
 - ▶ Trust that a partner is HIV-negative.
 - ▶ Good health and lack of symptoms of HIV infection.
- ***Lack of awareness about higher rates of HIV infection in their communities and among their peers and how those rates increase their risk.***
- ***The risks of being labeled, including:***
 - ▶ Concerns about rejection from sexual partners, friends and family, and awareness of resulting stigma within one's community.
- ***Perceptions of the consequences of living with HIV:***
 - ▶ Not having a strong sense of available treatment options.
 - ▶ Belief that people who test HIV-positive spend their lives emotionally depressed and physically ill.
- ***Limited routine healthcare, generally confined to symptom-driven medical visits or, for boys, school-related physicals.***

I know it's possible that I could have gotten it, but in most cases it isn't really possible. Condoms don't always work. There could always be chances where... I don't know, I don't want to think of it that way.

19-year-old bisexual Latino

The people...the person I did it with, she don't have it. I just know. I don't get tired. I haven't lost weight.

16-year-old African-American male

I don't think I'm at serious risk, but I don't think, "Oh, it's not gonna happen to me." I don't go and just hook up with any girl. I don't put myself in situations where maybe or maybe not it could happen.

18-year-old Latino

These days, girls have gotten too easy. Sleeping with them is too easy. Now, back in the day, it used to be complicated. But why would I want to sleep with something that easy? If it was easy for me, then it was easy for everyone else.

18-year-old African-American male

- **Lack of knowledge about available free or confidential testing sites for teens, combined with:**
 - Discomfort discussing sexual activity and behavior with family doctors and belief that testing by a family doctor requires parental involvement because of the need for insurance information.
- **The implication that a need or request for HIV testing confirms, if not to others, then to themselves, mistakes or incorrect behavior.**

INTERNALIZED EXCLUSION FROM RISK

Among the teenagers interviewed who have not been HIV tested, most reported varying degrees of HIV risk behaviors, including unprotected vaginal and anal sex, multiple and casual sexual partners and, for a few, intravenous drug use. In fact, nearly all of the teens interviewed, including those who have been HIV tested, acknowledged having had unprotected sex.

With very few exceptions, however, even while repeating the key prevention message that "anyone can get HIV," these young people were generally convinced that they personally have not been seriously at risk. Underlying most teenagers' sense of security and their decisions not to seek or agree to HIV testing are misperceptions and strong rationalizations about their risk behaviors.

Most of these teens, including those who have been HIV tested, are inclined to believe that they have indeed behaved safely by using condoms "most of the time" and have minimized their risks for HIV, other STDs and pregnancy. Because these teens judge the occasions when they have not used condoms to be infrequent, many contend they have no compelling need to be HIV tested.

Yet the unreliability of their judgments about the frequency or risk of their unprotected sex is demonstrated by numerous statements, expressed beliefs and reported miscues by teens themselves. For example, when asked how often condoms are *not* being used, some teens reported "about 25 percent of the time" or "*only* once a week."

It depends on who it's with. Not all the time, but I do use [condoms]. But if I've known her, then it's optional. It's the heat of the moment thing. I don't know, they could be telling me anything.

18-year-old African-American male

I don't have money to waste on condoms. I trust the pill.

Latino teen

Reduce the price of condoms or something. They're high. Sometimes they give you those old, white packets, the ones that you don't want to use.

18-year-old African-American male

I get tired of buying condoms all the time. She could buy them, too.

Latino teen

She was a virgin. I still use a condom, though. Not every single time, but you know...

18-year-old African-American male

It was protected sex with a condom, and later on it wasn't. She said she didn't have sex with other people, but I didn't believe her, and then later on I found out that she was a virgin. You know how girls are nowadays, how they dress. You would think, "Oh, she's a virgin," but you're not absolutely sure.

18-year-old African-American male

She's a very clean girl. She keeps up with herself real well. Oh yeah, she was a virgin also. She tells me everything, so I think she would have told me, "Oh, I want to go see a doctor," or something like that.

18-year-old African-American male

The two partners that I've had, I've known them for a while. I'm not saying I know their sex lives or anything like that, but...in my neighborhood, whatever you do, everybody finds out and they let you know.

17-year-old Latina

I didn't always use a condom. With the first one I did. With this one I never use them. We don't use any birth control. The first time was okay, and then it's like an addiction. It feels better. I know it's an excuse, but it's a reason.

19-year-old African-American male

Furthermore, when describing those situations in which condoms were not used, some teens would dismiss the risk by saying "it was with someone I trust," or "we've been together for four months" or "I pulled out," believing that by not ejaculating inside a man or woman they had diminished their exposure to STDs. By these rationales, teens perceive they have indeed acted safely; there is no need to worry about contracting an infection nor any reason to be HIV tested.

Notably, especially among young men, an additional explanation for the irregular use of condoms was their perceived cost. Where free condoms were available through school-based clinics, teens sometimes dismissed them as being "the white, cheap kind," criticized them as being "too thick" and said they won't use them "even if they are free." A few young men said they might use condoms more regularly if "good" brands were available for free. As one young Latina who distributes condoms in her school reported, "what they ask for is the assorted colors. That's all they ask for is the assorted colors."

Additionally, the research finds that some young men have internalized a sense of diminished risk for HIV, and the consequent need for HIV testing, because they have unprotected sex only with "virgins." In fact, several young men who have had multiple partners and have not been tested say they "only have sex with virgins" either by design or happenstance. When challenged about how they know with such certainty that their partners are virgins, the typical response was, "you can just tell," or "I ask them."

Among both young men and young women, perceptions of monogamy in relationships, however short-lived, and the emotional need to "trust" partners strongly contribute to lowered perceptions of risk and the belief that it is neither necessary nor beneficial to be tested for HIV.

Yet again, some teens confessed that they don't reveal sexual activity outside of their relationships to their primary partners. When speaking of her boyfriend's expected response if she were to confess her sexual affairs, one 18-year-old Latina remarked: "He'd kill him [the other guy] and then come and really mess me up." An African-American young woman commented:

Before we ever slept together he had taken a blood test and the results came by mail. When the results got to his house, I was there and we opened them together. I looked at the paper myself. That was the only reason I slept with him.

18-year-old Latina

I didn't see a doctor. What I did was that I had her tested for HIV and other things, put her on birth control, took care of her so she wouldn't get pregnant.

19-year-old Latino

No, [I'm not at risk]. Maybe, maybe not. I don't know. I'm not really worried about it. I should be worried about it, yeah. Maybe I think that if my boyfriend doesn't have it....I'm thinking about taking an HIV test. He told me he's never taken an HIV test...He told me he's used condoms, so I haven't been thinking about it.

19-year-old African-American female

I heard a girl that used to go to school with me caught AIDS.

18-year-old African-American male

In that school there's high AIDS population, but I don't know. Maybe it's just rumors.

19-year old Latino

As long as I'm just messin' with him, it doesn't really matter [that we're not using condoms]. If I thought he was messin' around I'd say something to him first. And if I felt he was lying, I'd go get tested. If I have to get tested, that means I don't trust you no more and we'd have to go back to using condoms, even if there is nothing wrong with me.

Additionally, knowledge that a partner has been HIV tested, particularly in the context of a relationship, decreases the urgency some of these teens feel about their own need to be tested. As a 17-year-old African-American woman explained it:

This guy I asked [to get tested] because I felt like we was going to be together forever. I had sex with him maybe about 30 times. [We] were supposed to go to the doctor together. He went. I didn't. I went with him, to see if he was okay. If he's okay, then I'm okay. This is just what I think. I don't know.

The complexities of teen perceptions of risk also surfaced with a 19-year-old Latino who until recently had been a sex worker and intravenous drug user. He supported his decision not to be HIV tested by contending that he only used "clean needles" and "always" wore condoms, although observing that they were not always reliable, with his tricks and with his girlfriend.

NOT HERE AND NOT AMONG MY FRIENDS

In the world of these American teenagers, HIV is a disease that strikes other people, older people, drug users and gays. Moreover, even though most of the young people we interviewed know people in their neighborhoods who have HIV, and often had family members who are HIV-positive or have died from AIDS, it rarely influenced their perceptions of the prevalence of HIV within their communities and how it may increase their own risks for exposure.

With rare exceptions, most often among a few young gay men, none personally knew someone their age with HIV and only a very few, through rumors, had ever heard of a teenager in their schools or communities with HIV. Teenagers understand that people their age get HIV, but they had virtually no recognition that infection rates are rising among those under the age of 25, particularly among young people of color. When told about increasing infection rates among teens, and that their cities rank in the top 10 for AIDS incidence among teens in the U.S., these young people

I wasn't really worried about it, but I was kind of scared, and plus I stayed in New York for a while and New York is like the AIDS capital and I was messin' with a dude up there and I got sick up there.

African-American female (Houston)

I wouldn't go messin' around in New York or anything. There's a lot of AIDS in New York.

18-year-old Latino (Houston)

Some girls get offended. I had that once. I took out the condom and she was like, "What, you think I'm dirty or something?" But that's because we didn't have a conversation about it first.

19-year-old Latino

Not where I come from do people brag about STDs. If you get an STD, I'm not messing with you.

16-year-old African-American male

They must have some reason to get tested. They must be worried about somebody they slept with or something.

19-year-old bisexual Latino

You're dirty. That's how we think of [people with STDs]. Most of the people that are sick are girls, in my high school. It's like, rumors always start and people talk. We just don't associate with them anymore.

17-year-old Latina

reacted with stunned silence, looks of alarm and genuine concern.

Generally, we found that teens expect the probability for coming into contact with HIV-infected people to be highest somewhere else, in places like New York City. In Newark, New Jersey, teens pointed to the visible New York City skyline and said infection rates and risk are probably highest there. Even in New York City, teens tended to say the problem was greatest in neighborhoods other than their own. "Probably it's in the Village," one remarked.

Overall, this lack of exposure to and awareness of HIV-positive peers, coupled with ignorance of the growing incidence of HIV seroconversion among people their own age in their own neighborhoods, is playing a powerful role in diminishing young people's perceived risks for contracting HIV, as well as the benefits of and need for testing.

THE RISKS OF BEING LABELED

Teens repeatedly discussed the challenges they confront in their search for intimacy, affection or satisfaction in sexual and emotional relationships. With near unanimity, both young men and women stressed that a reputation for promiscuity or a label of "not clean" as the result of having had an STD is a serious impediment to their ability to pursue those relationships, not only with potential sexual partners, but with their peers.

We found, however, that these labels were attached far more often to young women by the young men who were interviewed. Rarely did young women refer to young men as being "not clean." In a poignant reminder of the kinds of experiences these teens endure, when young women did talk about boys who were "not clean," it was with reference to a boyfriend who had given them an STD or, in one case, HIV.

Critically, many teens indicated that doubt and suspicion would be raised among their peers, especially those of the opposite sex, if it were known that they had even been tested for STDs or HIV. In contrast to the perceptions of some teen healthcare professionals during a preliminary roundtable discussion:

- Teens said they would only tell a very limited number of people that they had been HIV tested, usually "my best friend" or "my aunt who I can talk to," but rarely a parent.

I [got tested] by myself. I'd rather not have everybody know. Rumors spread and, next thing you know, your mother knows. You can tell someone, "I'm going to get an AIDS test," and they take that as saying you *think* you have AIDS and then the next person will say you *have* AIDS.

16-year-old Latina

It'll run through, like, "What were you doing? Unprotected sex? Were you doing drugs?" Stuff like that. To tell you the truth, [homosexuality] wouldn't even cross my mind.

18-year-old African-American male

It's like sentencing your life, being on death row, waiting for your time to come, as long as you got that virus inside your body.

16-year-old Latino

I'm the type of person that finds something like that out, two days later, you find me hanging from a tree. I don't know. I see my friends, how they are. Miserable!

19-year-old bisexual Latino

Everybody would look at you different. If you're on the block and the niggas know you got AIDS, they know you can't get AIDS by touching, but they don't want to smoke with you, they don't want to drink behind you, they don't want to touch nothin' you've touched.

African-American male

Sickness, and it kills your defensive, um, your defensive system. Your immune system. It's pretty much eating you away. You get skinny, all that kind of stuff. I don't really want to find out about it, even though it's good to know. I don't really want to look into it.

18-year-old Latino

- Teens believe that, regardless of the results of an HIV test, rumors will start to circulate that you might be positive if others simply hear that you've been tested.
- Teens do not boast about HIV test results (unless negative results are being used to further a sexual conquest) and never want others to know that they have been tested for other STDs.

An important finding surfacing in these interviews with teens is that HIV is clearly *not* perceived as a "gay" disease and there is little concern that being HIV tested will raise questions or suspicions about their sexual orientation. While fully aware that gay people are at risk for HIV, the teens interviewed, with very few exceptions, primarily associated HIV in their communities with drug use and promiscuity. For them, HIV and AIDS, and HIV testing as well, do not carry a "gay" stigma.

PERCEPTIONS OF LIVING WITH HIV

No matter what personal interactions they might have had with people with HIV or AIDS, teens have strongly pessimistic views of what life is like for HIV-positive people, often believing the inevitable consequence is depression, ostracism within one's community and a sickly, wasting body. These views strongly contribute to young people's reluctance to be tested. And as described in subsequent sections of this report, fear of living a life with HIV creates tremendous emotional turmoil for them during the days and weeks of waiting for test results. As one 17-year-old African-American woman simply exclaimed: "If I'm positive, I don't want to know it."

For teens, both those who have been tested and those who have not, the mere contemplation of taking an HIV test instantly evoked the nightmare of being given a positive result. When asked to describe what life would be like with HIV, teens often responded with visible revulsion—shivering body language, wincing, shaking heads, hands waving frantically—all the while saying "It's awful," or "It's scary" or "I don't even want to go there."

Some said they would want to die, while others said having HIV would result in an inevitable loss of friends, that people would treat them differently or that they wouldn't be able to have sex or children anymore. As one young African-American man who has not been tested remarked:

I think it makes you lose your friends. If someone wants to have sex, and their partner knows they have AIDS, they can't have sex.

19-year-old African-American female

In my neighborhood, if somebody got AIDS, excuse my language, but they would be called a ho, a bitch, a slut. They wouldn't be questioning if they were gay. No. In my neighborhood, if you're gay, you get shot. You get teased.

17-year-old Latina

I learned that anybody could get it. Magic was my favorite player at that point. I felt like crying myself. I was like, "Magic's going to die, man." That's kind of how you think. But it's like there's still hope; a second chance or something.

18-year-old African-American male

In order to treat AIDS and live, you got to have money, like Magic Johnson. It's not even in his blood right now. He paid for that.

African-American male

Some of them, most of them [live for] four years, if you keep yourself up, go to your counseling and take care of yourself. You can't really cure HIV, but you could slow it down a lot. Like Magic Johnson. He's got little or none left.

18-year-old African-American male

In school, my teachers educated me that once you have it, there's no getting out of it. You're going to die, no matter what. There's no way of surviving.

17-year-old gay Latino

I was watching this TV show one time and this man was talking about these pills that are prescribed by your doctor. But you got to pay a pretty penny for them...I know they cost a lot of money, but I don't know if they really help.

18-year-old African-American male

There's already rumors saying that there's a cure for AIDS in Africa and different places like that. They say we can't have it because we're not used to the way they use their medicines.

African-American male

It's scary. It jumps on my mind. I don't want it. I want to live my life to the fullest. I want to have kids and I don't want them to have it. I wouldn't do anything, just sit around the house. I wouldn't go to school, probably wouldn't go outside. Heartbroken.

It's also important to note that Magic Johnson continues to be a powerful influence on young people's understanding of what it means to live with HIV. Although they were just children when the news of Johnson's positive status was announced, they remember it clearly because they expected he would die quickly. "I felt like crying," recalled one African-American teen.

Yet, as some explained it, Johnson's longevity and apparent good health has been perplexing, prompting curiosity about why his wife is HIV-negative and beliefs that he is still alive because he has money and can afford to buy the right drugs. Nevertheless, talking about Johnson's life generally seemed to dispel in these teens' minds some of the more negative images of people with HIV, which for most of these young people is that of a skinny, sick and desperate drug user.

THEY DON'T KNOW ABOUT TREATMENTS

Another significant barrier to HIV testing among young people and a factor that strongly contributes to their negative perceptions of the disease is a profound lack of information about available treatments. This condition adds to a sense of hopelessness about a cure, and the belief that one usually dies within five to 10 years following infection.

Young people's knowledge about treatments for HIV was generally confined to the belief that "you can take pills that will make you live longer." Some added the notion of taking "lots" of pills, while others reported that treatment is available only to those who "have a lot of money."

Although some teens said they believe a cure does exist, these beliefs appear to have been formed as a result of the urban mythology about a government conspiracy to withhold the cure from people of color. When challenged and addressed with medical information, however, these convictions seem to soften. For instance, several teens noted that recent news stories they had seen about the "discovery" of a link between HIV in humans and in chimpanzees had led them to rethink some of their assumptions about government conspiracies surrounding the origin and spread of AIDS.

Once I hit my teenage years, I was like, okay, I need to start getting taken care of. I kind of matured faster than most of the kids I grew up with.

17-year-old Latino

I became sexually active around age 13. I didn't see any doctor. I just felt I knew what I needed to. My aunt said this used to be a hospital. Now it's a clinic. She didn't tell me about it, but I told her where I'd been when I got home.

18-year-old African-American male

He is the best doctor. I feel comfortable with him. He's not going to tell me his opinion about anything.

17-year-old Latina

I don't know if I have insurance or not. I'd go to a doctor somewhere in the Yellow Pages. I mean, they have that in the pages. I'm sure they do.

18-year-old Latino

I don't really have a doctor. I don't really know how to find one.

18-year-old African-American male

My mother still comes to the doctor with me. I can't go to the doctor by myself. I don't know how it works. *19-year-old African-American female*

We called a lot of clinics before, but they said it was like \$70 for each screening, \$150 if you wanted to do everything including HIV. We found out about the free clinic, so we decided to go with the free clinic.

18-year-old Latina

ACCESSIBLE TEEN HEALTHCARE

In screening questionnaires administered prior to the interviews, teenagers participating in this study were asked to describe the kinds of health insurance, if any, they have. In response, only one-quarter reported to be covered by private health insurance, typically through a parent's plan, while nearly four-in-10 said they did not have any health insurance coverage and three-in-10 said they were covered by Medicaid. Overall, most of the teens interviewed say they are receiving healthcare at clinics, but the choices of which one to use or where to go for healthcare services often varied depending on the reason for a medical visit.

The healthcare needs of teenagers are in transition and this appears to have a strong impact on their consideration of HIV testing. The research suggests that:

- Unless young women experience a “problem” or young men need a physical to participate in sports, teenagers said they generally do not see doctors for routine healthcare.
- Teens are deterred from seeking healthcare and HIV testing when they sense that medical office and clinic workers don't “respect” them or are “judging” them for being sexually active.
- Although young women seemed far more knowledgeable than young men about where to find healthcare services beyond emergency care, awareness of healthcare facilities that will address sexual needs and conduct HIV testing vary from teenager to teenager. Some teens had no idea where they would go if they wanted to be HIV tested and said they would probably “look it up in the Yellow Pages” if they wanted a test performed.
- Confidentiality concerns impact where teens will go for healthcare. Some teenagers said they simply won't discuss their sexuality or sexual health issues with pediatricians or family doctors who have known them since childhood. Others said they will not get tested for HIV if it means having to ask their parents to arrange an appointment or provide parental medical insurance information. Often this parental involvement means that teens risk revealing that they are sexually active to their mothers or fathers.

Whatever's convenient, or moneywise, whichever is cheapest.

19-year-old Latino

They asked me, do I want to take [HIV]. I just wanted to be sure when they brought it up. Herpes, I used a condom when I contracted that. Hepatitis B, I don't think that was from sex. PID, I don't know. The warts, I used a condom, too.

16-year-old African-American female

My doctor, she tells [my mom] to step out of the room. Then she asks me questions like, "Are you sexually active?"

15-year-old Latina

I wouldn't talk to him [my doctor] about sex. It has nothing to do with how old he is. I'll talk to my friends. It has nothing to do with them being smarter than him, but I just feel more comfortable with them, because they know me on a personal level.

17-year-old African-American male

They started [a clinic] over at the high school with the nurse. If the nurse couldn't do something, they would recommend that you go to the teen clinic which is in the far back of the school in its own section. They do physicals for sports, too. It's very reliable.

19-year-old Latino

Most of the girls would go to the clinic downstairs when I used to go to school. They would get there and they would send them somewhere else to get tested.

17-year-old Latina

- Having to pay for HIV tests is a significant issue for teens, as most indicated that "free" tests played or would play an important role in their decisions to be tested.

Overall, the research suggests that young women are far more likely than young men to seek out healthcare services, particularly when it relates to sexual issues. Young women are most often prompted to seek out clinics or medical providers by the desire for birth control, pregnancy tests or experiencing "discharges" or other symptoms suggesting a possible STD. Notably, nearly all of the young men said they felt no need to see or talk to a doctor once they became sexually active. Young women, on the other hand, clearly expressed a sense that their healthcare needs had increased because of their sexual activity.

Those teens whose only source of medical care continues to be their childhood pediatricians nearly always said they were inhibited from having frank discussions about sexuality and sexual health issues because "he knows me" or "knows my mom." Underlying these statements were concerns about breaches of confidentiality, that parents would be informed if something was wrong with them, and fears of judgmental attitudes from healthcare professionals because of their sexual activity.

Furthermore, some young men and women report that their mothers accompany them to doctor's visits, another factor inhibiting candid discussions about sexuality and sexual issues. Nevertheless, several young people did feel their pediatricians or family doctors were "cool" enough to share sensitive information with and to be asked for HIV testing. Several young women did note that their doctors had assured them that their conversations would be confidential and had asked that their mothers, when present, leave the room.

Among those teens who had access to confidential health services at high school teen clinics, most said they felt comfortable going to such clinics because they would not stand out in the waiting room: "you could be there for any reason." Several young women did, in fact, indicate they used high school clinics for "free pregnancy tests." Nevertheless, opportunities for HIV testing are being missed because testing was not offered at these clinics, even though some teens had requested them and were referred to other testing facilities. Beyond getting physicals to play sports, many teens said they only went into these clinics to pick up free condoms.

I don't like this clinic anymore. They wouldn't let my partner in the room. The lady was rude to me. She was shitty and mean. She didn't want to listen...The nurse was snobbish.

16-year-old African-American female

The nurse...kept asking me if I wanted to be pregnant. Like I'm ignorant, to belittle me because I'm young and I'm having sex. And I didn't feel that it was right, because at least I was responsible enough to use birth control and condoms and make sure I was alright, that I wasn't being hurt. I didn't like how they treated me.

16-year old Latina

She was real mean. I like doctors that communicate with you, not just go straight to their jobs. She was too straightforward. She was too honest. "I don't care what you think. Lay down." She was a real bitch. I felt like hitting her."

17-year-old bisexual Latino

The [teen clinic] is such a great place. They make you feel comfortable everywhere. I always felt scared of the reality if I had it, but I didn't feel scared of getting judged or criticized or any of that. It was clean, and while they were doing it they kind of said, "Well, I'm going to do this to you and this is why I'm doing it."

Gay Latino teen

Attitude and treatment by healthcare workers appear to be major factors in drawing young people into or deterring them from the healthcare system, particularly for sexual healthcare including HIV testing. Teens appear hyper-sensitive and highly attuned to the "attitude" of staff at clinics and other medical facilities. In fact, several young women expressed anger at public clinic workers who they believed displayed a lack of respect toward them, prompting some to walk out of clinics soon after they arrived. In one case, a young Latina had gone with a friend specifically to be tested for STDs but soon left in anger. She subsequently went to another facility and was HIV tested, but reported her initial experience as follows:

When I went to get the STD screening and we were late, the lady was super rude. I wanted to smack her in the face, but she was behind the glass. They told me when I called the clinic that they closed at five. I got there at three. She goes: "You have to be here before three. If you're here after three, then I can't take you." She was really rude about it and I was going to tell her, "Fuck you, I'll go somewhere else." But I didn't. I just left. I have a really bad temper so my friend pulled me and said, "Let's go." I don't like people being rude to me. I respect everyone but don't be rude to me and disrespect me. She was being really rude. If she doesn't like this job why is she working here?

In contrast, teenagers with experiences at *teen* clinics nearly always reported a positive, engaging and caring experience with both staff and clinical personnel. Despite mild irritation at being "kept waiting," teens often strongly expressed the connections they had with teen clinic staff members who seemed to satisfy young people's expectations for professional and respectful treatment. Relating her experience at one teen clinic, a 16-year-old African-American woman said:

They talked to me and my partner and gave us individual attention. They dealt with my situation on an individual basis, not like just trying to get me out of there. They offer counseling, too, about medicines and everything. They are wonderful. It's newer looking, cleaner.

As noted later in this report, one of the key motivations for HIV testing is encouragement from a healthcare professional who suggests HIV testing in conjunction with teen requests for pregnancy or STD testing. When young people are disconnected from health professionals with whom they can frankly discuss their sexuality and sexual health issues, the opportunities for HIV testing recommendations are

My doctor asked me if I wanted to get tested and I said, "Yeah." The doctor I was going to before I started going to her, they didn't do stuff like that.

16-year-old African-American female

I have good health, so I don't have to worry. Every time I go, he's like, "How much do you weigh? How tall are you? Do you have any pains?" That's it.

17-year-old African-American male

People can get raped, but besides getting raped it is your fault. People can share needles or sleep around, and it is your fault. It's partly your choice. You give your body to them.

18-year-old white female

My mother warned me, "Don't do this," and you go right ahead and do it. So this is something that you'll feel guilty. Or, "I trusted him," or "I trusted her, why didn't he or she tell me?"

17-year-old bisexual Latino

I was crying. I was scared. My age, I really haven't lived my life. I was thinking, if I have HIV, what am I going to do? I'm going to die and you're dying from something that could have been prevented.

19-year-old African-American female

I just did not want to hurt my mother. I don't think my mother would ever do that [reject me], but I think I would get very shamed.

16-year-old Latina

I was hoping I was negative. At first, I was thinking about how I was going to tell my parents.

18-year-old African-American male

I was worried, if I would have had it, if my mother would treat me different. Like going to school, if I would have seen my friends. It would have got around the whole school and they would have been treating me different.

17-year-old African-American female

significantly reduced. Importantly, even in clinical situations where teens reported they felt comfortable talking about sexual issues, a few young people noted that medical professionals did not discuss, offer or suggest HIV testing when, according to teens themselves, they would have been open to that recommendation.

ADMITTING INCORRECT BEHAVIOR

These high-risk teens have heard the prevention messages. Virtually all of the those interviewed have learned through school-based programs that "anyone can get HIV" and that "unprotected sex" puts them at risk. Yet despite such education, and as noted earlier, most teens reported recent or current unprotected vaginal, oral or anal intercourse. Even though teens perceived diminished risk by having protected sex "most of the time," occasions of unprotected sex often brought into these teens' consciousness the education message, especially when relationships had been brief or "one-night stands."

Usually because of second thoughts about episodes of unprotected sex, and fear of a positive test result, one senses that to these teenagers, the very idea of being HIV tested compels the difficult admission, first to themselves and then to others, that they have behaved incorrectly.

Both tested and non-tested teenagers speak with deep anxiety about the inescapable process that testing sets into motion: of having to tell a partner and a mother of a positive test result. Teens who have been tested say they only volunteer to others that they have been tested once they know the results are negative. Negative test results are seen as affirmation of "good" behavior and an assurance to potential sex partners that they are "clean."

At the same time, a few untested young men said that they did not want to know their HIV status and would not be tested unless something was wrong because they "didn't want to have to change" anything they were currently doing.

I think I'd go get tested after a certain amount of partners, just for the hell of it, even if I know they're okay or whatever. If I were to use a condom, no. But if the condoms would break, yes.

17-year-old untested Latina

I wanted it for myself because, you know, you learn in school and everything else that if you have unprotected sex, you should get it checked out to make sure.

18-year-old African-American male

A lot of times, if I go with a girl, I start thinking, "Why does she want to do it with me?" It just pops up in your head and you start being insecure. She must be cheating or something.

16-year-old African-American male

CHAPTER TWO: TESTING MOTIVATORS

The research conducted with both HIV tested and non-tested teenagers suggests that the factors stimulating HIV testing generally fall into broad categories: personal concerns about risk behaviors and potential exposure to HIV, recommendations of caring people and healthcare professionals, availability of "teen friendly" testing sites and effective HIV prevention education and outreach programs targeted to higher risk youth. Overall, we found that teenagers who *have been* tested split into two groups: those who were self-motivated and took action themselves to be HIV tested; and those who, with a gnawing uneasiness about their HIV status, impulsively agreed to be tested when encouraged by healthcare professionals.

Importantly, regardless of sex, sexual orientation, race or ethnicity, underlying most teenagers decisions to be HIV tested were nagging concerns about possible exposure to HIV after occasions of unprotected sex. Apprehension about the severe consequences of unprotected sex, a worry stemming from the HIV prevention education messages they had heard, was also the clear emotional link prompting non-tested teens to consider HIV testing. When asked what would motivate them to be HIV tested, non-tested teens most often said: "If I learned that [my partner] was sleeping around, I would go get tested."

According to the research, the major influences motivating young people to be HIV tested include:

- ***Fear of possible exposure to HIV and the need for emotional relief from uncertainty.***
- ***A firm belief that the results of an HIV test "will come back negative."***
- ***Access to testing facilities that satisfy teenagers' needs for confidentiality, low-cost services, convenience, and a caring attitude.***
- ***Recommendations for testing by doctors and other healthcare professionals during routine physical exams or visits prompted by teens' health concerns.***
- ***Concern for one's physical well-being and for the health of sexual partners as well.***
- ***Encouragement by parents, partners or "best friends."***

■ **School-based education and youth-service outreach programs that inform teens about HIV and AIDS, risks and testing facilities.**

FEAR OF EXPOSURE

Nearly all of the teenagers interviewed reported having had unprotected sex, and often in the same breath they acknowledged their behavior to be “unsafe.” While the research indicates that young people don’t always behave in accordance with the HIV-prevention lessons they’ve learned, they *do* strongly believe what they’ve been taught about HIV: that “anyone can get it” and that they should always use condoms for “protection.”

Although these young people, as individuals, often judge others to be at higher risk for HIV, in no case did we find teens ignorant of the basic rules of HIV prevention. The assertion of one African-American young man, who reported “somewhere between 10 and 20” partners and using condoms “maybe 90 percent of the time,” was typical: “I know the consequences of having HIV and STDs and stuff like that, so I’m going to use a condom to protect myself from catching it.” And dismissing any notion that she was unfamiliar with the risks of unprotected sex, a 17-year-old African-American echoed the comments of many of her peers: “It’s not like, ‘Oh my God, what is HIV?’ This is 1999.”

Nevertheless, many teens admitted they are not using condoms in their “serious” relationships because they believe those relationships to be monogamous and they “trust” their partners. Most of those who said they were currently in a “serious” relationship did not feel a strong need to be HIV tested. Notably, although curious, very few knew their partners’ HIV status, assumed it to be negative, and stopped using condoms after several months, not because they had any *new* information about their partners, but because condom use “got old.”

But the end of a relationship or information that a partner had cheated was very often the motivator prompting a teen’s decision to be HIV tested, as it was for one young woman who said:

I wanted to know because my ex-boyfriend was older than me...I was 14 and he was 21. At that moment I didn’t think about anything. But dang, I was talking to my friends and

I was shook. I couldn’t find [a condom]. When it [unprotected sex] first happens, you think about it [a little]. But then the feeling be overpowering you. Afterwards, you might not even be thinking about it, then it just pops into your head. That’s when it really bothers you.

African-American male

I’m not saying I’ve used a condom every time I’ve had sex, ‘cause I know there’s been a lot of times when I haven’t used condoms. But I was in a steady relationship for a year and a half. We knew each other very well, so it’s not like we were...

Latino teen

The girlfriend I have now, she’s on birth control. We still use condoms, but we slip up. Birth control is not 100 percent and I don’t really know if she’s sleeping with anybody else.

18-year-old African-American male

We were together, so I assumed he was monogamous. It think it was when we broke up and they were saying, “He’s been around.” So I thought, “Let me go and be safe before you get into another relationship with somebody else.”

Gay African-American male

We was using condoms at first. I knew I wasn't seeing anybody else and I can't see where he fits this little time in to go see somebody else. So, after maybe five or six months, we just stopped using condoms.

19-year-old African-American female

I had an encounter, let me see, I had a sexual experience and I used a condom, but the condom broke. I was terrified, because you know, here I am, I did the right thing, but...And it wasn't like somebody I really knew. It was a casual experience.

Gay Latino teen

In the ghetto, sex gets you money...I'm young. I'm good stuff, but my stuff's all wrapped up in using people.

16-year-old African-American female

I wanted to go to Mardi Gras and I heard that there are people with HIV who are sticking people with needles. They said it feels like a mosquito bite and then you have HIV.

16-year-old Latino

everything and it gets to you and he had been with I don't know how many girls. How was I supposed to know?

Reminding us that teenage sexual relationships are like the flame of a match—intense, but brief—teens often talked about their experiences with casual sex and “one-night stands” and frequently reported that their “serious” relationships had lasted only a matter of months.

Anxiety about possible exposure to HIV and the eventual decision to be tested could often be linked in these interviews to lurking doubts about either their own or their partners' risky behavior. It's also important to note that, for a surprising number of young people, concerns about HIV exposure resulted from a condom breaking during sex. For one 18-year-old, all these factors were the source of her anxiety. She had been HIV tested, she said:

'Cause I went out with my first boyfriend again after we broke up and he was sexually active with his girlfriend. But from what I heard on the street, she was cheating on him and he was cheating on her and I'd been with him and the condom broke and I just wanted to make sure.

In every city, we also detected concerns about exposure that were prompted by reports, rumors or simple supposition that some HIV-positive people deliberately try to infect others. In both Houston and Miami, for example, teens recounted similar stories about people sitting on HIV-infected needles that had been intentionally placed on movie theater seats.

In Miami, there were repeated stories of HIV-positive people “sticking” kids in the clubs. In New York and Newark, teens told of hearing that people had been “stuck” as they reached into public telephones for their change.

For one 17-year-old African-American woman, belief that HIV is being deliberately spread was founded on more than mere anecdote or rumor. She personally knew that an HIV-positive family member was having unprotected sex with an unknowing partner:

I don't want to end up like her. I have other family members who passed away from AIDS. She hasn't told the guy she's with that she's HIV-positive...I'm feeling like it's my fault. I want to tell him, but I can't tell him.

...Last year, I was like, “Well, I’m getting older. I might as well [get tested]. I’m pretty sure I don’t, so I might as well just go ahead and do it and get the results back, ‘cause they’re going to be negative, anyway.”

17-year-old African-American female

Me, I’m sure of myself. I just want to do it to make sure. But I know that it would never happen to be like that, ‘cause I know what I have done. Twice it happened to me [the condom broke]. But I never, like, kept going. Plus, most of the people I’ve been with, I’ve been very sure about them.

15-year-old Latino

I don’t know, I just don’t trust [public clinics] that much. It’s just that I don’t feel comfortable going to a place like that, not knowing who you’re talking to.

17-year-old Latina

I had a situation where I was scared and they [at the youth center] just sat me down and told me these are the services we can do for you. The people I’ve encountered in terms of services and HIV testing and stuff, they present the information more than my doctor.

20-year-old gay Latino

CONFIDENCE THAT THEY ARE HIV NEGATIVE

Most teens, both those who had been tested and those who had not, said they felt “confident” or “certain” that their HIV tests would be negative. More than anything, by seeking or agreeing to HIV testing, these young people were searching for peace of mind. They wanted “to be sure.” In the words of a 16-year-old Latina:

At first, in my head, I was like, “I know I don’t have AIDS.” But then I was like, “Well, I am having sex,” so I just took the test, ‘cause you can think you trust somebody and know them so much, but you can never be too sure.

ACCESS TO HIV TESTING FACILITIES

Multiple comments and issues surfacing during the course of these interviews suggest that increased availability of or access to youth-oriented healthcare services in general will increase the likelihood that teens will seek or agree to HIV testing. Although many teens were HIV tested at public clinics and a few at doctor’s offices, we repeatedly detected among teens a greater level of comfort about receiving general healthcare and advice from professionals at facilities specifically designed for teens, including school-based clinics. As one young woman said of a free teen clinic she frequented:

They talk to you a lot. They’re not mean like regular doctors. The regular doctors just throw the medicine at you. The others [at teen clinics] sit down one-on-one and explain everything that’s going on, your options. That makes you feel so much better.

Consequently, when professionals at these youth-oriented facilities advised STD or HIV testing, young people seemed more open to accepting their recommendations and agreeing to testing. The increased opportunity to successfully motivate HIV testing by healthcare professionals in this accessible environment was demonstrated by the comments of one 16-year-old African-American man:

It’s a school clinic. I used to go down there and just get check-ups, physicals, whatever. Tests for hepatitis. One time there was a counselor who talks about AIDS and stuff and she said, “Why don’t you test for HIV?” She made it exciting. She was just laughing and joking and whatever. [The clinic] is built right into the school. You can get condoms. It’s always confidential. Nobody finds out unless you want them to.

If I was at risk and real scared, but knew I had to do it, I'd come here [to the counselor at the youth program]. She's like my aunt. My best friend. And she'd not pressure me, but give me the actual push I need [to get tested]. I know they'll give me the right answer. I guess trust is the first priority for me.

17-year-old bisexual Latino

It would have to be a place where they're very friendly and they're going to be very helpful. They would walk you through everything. Sit you down and explain things that would make you understand. Like sit down, ask my name, introduce themselves, talk a little bit about me, talk a little bit about themselves. So you could get more calm. So you could go out there and get tested and be like, "I'm strong." They could help you out like that.

16-year-old untested Latina

I was panicked, [because of fear of STD]. So when the van came, I got tested.

19-year-old African-American female

Although not explicitly expressed by teens, it appeared that part of their willingness to be HIV tested was linked to a belief that should their test results come back positive, there would be someone at teen-oriented clinics who could help them, both emotionally and physically.

From the perspective of gay teens, one 17-year-old Latino also stressed the importance of clinics where doctors understand gay and bisexual youth: "[The teen clinic] is very cool about homosexuality and all that. They didn't ask me a lot of questions."

Young people who have been HIV tested at teen-oriented or other clinics also frequently noted that the availability of free tests was an important factor that motivated them to be tested. "There's a doctor in my school from the clinic," said an 18-year-old African-American man, who continued:

He told me they were giving out HIV tests and we didn't have to pay for them or nothing like that, so why not? I'm eager to know. It's just something I felt I needed to know, especially if you're sexually active.

In addition, assurances of privacy and the security of knowing that test results would not be shared with parents were also critical issues impacting testing decisions. Often, like one 18-year-old Latina whose parents don't know she is sexually active, teens said they seek out free clinics to insure that parents are not involved: "I was afraid to tell my mom to call the doctor's office to schedule an appointment and all that. I have to ask my mom for the [insurance] number and she has to know."

A number of HIV tested young women said the easy accessibility of mobile health vans sponsored by outreach organizations they knew and trusted prompted them to be HIV tested. As one of these teens remarked:

The van stops at places where they know people that are homeless or they doin' things there. I was just sitting there, curious about [being tested] anyway, so I just did it. I trusted them because they knew the people [at the shelter], so I knew I could trust them with my safety. It was just like a hospital. They had the badges on and everything.

They was taking blood...and they tested with the HIV and blood and all that stuff. I signed a paper or something. They asked me do I want to take HIV? I said, yes.

16-year-old African-American female

I came to pick up the birth control and that's when she told me that if I wanted it, I could take an HIV test. So I said, "Yes."

16-year-old Latina

You know your body's healthy. And what's wrong with you if you are positive. What to do if you are positive.

19-year-old African-American female

I was curious. I'm really curious about my body and I like to take care of my body and I felt like that was a major important thing that I need to know about.

17-year-old African-American female

I met my boyfriend now...and I was sleeping with him, and we weren't using condoms, and I was like, "What if I get him sick?" So I got tested for everything.

17-year-old Latina

PHYSICIAN RECOMMENDATIONS

Overall, many teens said they were prompted to be HIV tested simply because their doctors had suggested or recommended it. For a few young men, this recommendation came during routine physicals for school: "I went for a physical and they said, 'You gotta come back and do a blood test,' so I went back and did a blood test."

For some young women, HIV tests were suggested during appointments they had made to obtain contraceptives or following diagnosis of an STD such as chlamydia or pelvic inflammatory disease.

Importantly, a number of teens said that physicians or other healthcare professionals had circumvented the agony of asking for an HIV test by offering to do it "as long as they were taking blood anyway." As one 16-year-old Latino said:

I came because of something else. I told them, "I think I have an STD." They told me they could do the whole thing, get the blood test and all that and get tested for HIV, too. And I said, "Mmm, okay."

CONCERNS FOR PHYSICAL WELL-BEING

Among the teens who were tested for HIV, we found some who said their primary reason for getting tested was the strong desire to protect their own health. These young people, both young men and young women, said HIV testing was a demonstration of "caring about yourself." Some added that it was important to "know what's going on with your body."

In contrast, however, and no doubt linked to their generally negative perceptions of HIV treatment options and availability, only a very few of the teens we interviewed indicated they were motivated to be HIV tested because they would be able to start treatments. We do believe that educating young people about how treatments are available to those without money and are extending the lives of people with HIV would encourage many to be tested.

Another emotional factor that can be linked to HIV testing is concern about protecting the physical well-being of partners. Numerous young people, both those who have been tested and those who have not been tested, indicated that they would "never" want to infect another person with HIV.

I think the good thing about [getting tested] is that if you have it, you could give it to somebody you care about. You might feel very bad after that.

16-year-old African-American male

I couldn't just not tell [my boyfriend, if I was positive]. If I got it then he got it. It wouldn't be right. Because we could end up breaking up and he could give it to somebody else.

19-year-old African-American female

Me and my mother went to the hospital for me to get tested. She said that she sees that I'm maturing. She was proud, too, because she sees that most of these teenagers are out here having sex and they don't get tested. So she was really excited.

17-year-old African-American female

It was at a clinic. I was recommended to go there by a doctor and I went with my mom. We both went to get tested. [The doctor] knew I was sexually active and at the time my mom was seeing a man who she thought was cheating on her, so she was worried. It's good to have somebody else there to lean on.

17-year-old Latina

My girlfriend brought me in. She wanted to get checked; pregnancy and STDs and AIDS and all that, so I said I'd get checked, too. Just to be sure.

18-year-old African-American male

I don't think I'm at risk, because sex isn't that important. Some of my friends, it's a big deal. Trying to get girls. When I go out, I don't prey on girls. If it pops up, then yeah, but it's not the main purpose. Before I didn't really care about it. It wasn't a big thing. But now, all these doctors came to the school and showed pictures. It got through my head. I was kind of worried. I'd had unprotected sex once or twice.

16-year-old Latino

While young men in one session talked with a degree of bravado about not caring about some of the women they had sex with, they became silent and pensive when they were asked how they would handle telling a girl they cared about that she should be HIV tested. Moreover, several young people say their main reason for being HIV tested was the desire to know they were "clean" and would not infect another person. These kinds of feelings appeared particularly strong when new relationships were forming.

REACHING OUT & WORDS OF ENCOURAGEMENT

A key finding of this research is the strong role that parents, partners and peers play in encouraging young people to be HIV tested. In fact, we found that some teens made the decision to be tested solely to satisfy the concerns of parents, usually their mothers, or because their parents, recognizing that their children were sexually active, told them it was a responsible thing to do.

Although only a very few, some teens told us that they went to be HIV tested with their mothers. In the case of one gay youth, he said his mother's presence gave him the emotional support he needed. In another case, one Latina teen said her mother also got tested because she learned her boyfriend had been cheating on her.

Other young people say they were encouraged to be tested by their partners. The scenarios varied, but HIV tested teens say either they or a partner would:

- Be tested themselves and then apply pressure for their partner to be tested.
- Would be tested themselves so that they could show the test results to a partner.
- Would be tested together, although this was sometimes motivated by the desire to have unprotected sex.

Peer educators and community outreach programs also appear to have been a strong influence on some teens decisions to be tested and, according to some non-tested teens, are the groups they would turn to when they decide to be tested. Peer educators, young people talking to young people, appear to be very effective at informing teens about places where they can go to get health care, counseling and other social services. In all cities, we found referrals to clinics and social services to be often based on a strong word-of-mouth communications network. The key phrases among the young people that distinguished community-based

If I came out negative, I might tell [friends] that. I don't see the need to make a comment about it, but it would make me more sure of myself. If I get tested, it's not for other people to find out. It's just for me.

18-year-old Latino

When they first started coming into school and teaching us about sex and condoms and all that, in my mind, I was like, "Man, I'm gonna go get checked," because people tell me I'm skinny.

16-year-old Latino

When I was in elementary, these people come to the school and talked to me. They're like, "You never know who have HIV. They could be fat, they could be skinny." So I thought about it before. So when they came to the high school, I thought being as I was having sex, I should [get tested].

17-year-old African-American female

In my class, we had 30 kids, and he handed out index cards around the class and one of the cards had an X and that kid was supposedly HIV-positive. Then, later, he was like, "one out of so many kids are HIV positive. That's how many people at your school would have it." It gets you thinking.

Latino teen

organizations was "you can trust them" or "they're cool," or "I feel safe with them."

In strong contrast to the perceptions of health care professionals who were interviewed in advance of the teen interviews, virtually all of the teens we talked with said they did not and would not get tested with a *group* of friends. While it was common for teens to say their "best friend" traveled with them, they rarely indicated that both of them were tested at the same time.

Moreover, beyond a best friend or partner, teens say they never want others to know that they have been tested, even if the results are negative. According to teens, the mere act of being tested, when filtered through the grapevine, implies there's a possible reason for concern. For young women, the labeling is especially damaging to one's reputation. Moreover, although teens who have been tested appear very comfortable discussing the experience amongst themselves in a focus group setting, we are certain the dynamic would change dramatically if the group included both tested and non-tested teens.

SCHOOL-BASED HIV EDUCATION

Throughout these interviews, teens frequently referred to "what I learned in school" about risk behaviors and their consequences. And it is this very information that resurfaces and nags at teens as they consider HIV testing. Prevention education tactics and messages that appeared to be deeply compelling to them included:

- Messages delivered by healthy-looking HIV-positive people who drive home the concept that "you can't tell by appearance." One 16-year-old African-American male, for example, remarked on the continuing impact of a presentation made in his elementary school by an HIV-positive ex-prostitute: "I like pretty eyes. She had hazel eyes. She just caught my attention. I still remember it."
- Games and exercises that graphically and simply reinforce the notion of easy and unknown transmission from partner to partner.
- General, continuing and positive education and information about HIV, risks, prevention and availability of testing.

CHAPTER THREE: HIV TESTING EXPERIENCES

The variety of sites at which teens reported they had received HIV tests included hospital-based public clinics, youth-oriented teen health clinics, outreach programs both in street vans and on-site at teen agencies, health department STD clinics, reproductive health and other non-hospital-based clinics and private doctors' offices.

Among the teens interviewed, the site at which they were first tested was frequently less the result of deliberate choice and more the result of being offered HIV testing at clinics or doctors' offices during visits for other healthcare needs, or of taking advantage of the immediate availability of HIV testing through outreach programs in street vans or at community-based teen service organizations.

One Latino teen expressed an almost nonchalant attitude toward decisions to be HIV tested by saying: "They made it mandatory that kids get hepatitis and tuberculosis [tests] no matter what, so some do HIV at the same time."

Nevertheless, teens who were self-motivated to actively seek HIV testing, including several who had been tested numerous times, were influenced in their decisions about where to be tested by many of the same factors they use to judge and choose healthcare providers: prior experiences at or familiarity with specific healthcare facilities, considerations of cost, confidentiality, ease of access, level of comfort with staff and environment and referrals to available HIV testing sites by peers, medical professionals or teen counselors.

Although some teens were tested anonymously, and others avoided doctors who knew their families, a *need* for anonymity was never a specific issue raised by any of these teens, either those who had been tested or those who had not.

TESTING METHODS

Of those teens interviewed who have been HIV tested, the vast majority had been given blood tests, often in conjunction with having blood drawn for other testing procedures. Fewer than one-in-ten were given oral HIV antibody tests and none said they had used an over-the-counter, home HIV test, although a very few volunteered they knew others who had used it.

I went for another problem [to the community clinic], and they asked me if I wanted to get tested. But twice, I came up here [to the teen clinic] just for that, just to get tested. I didn't wake up and say, "I want to get an AIDS test today." The good thing about it is to just find out. You see things on TV and you think about yourself automatically. You don't just want to sit around wondering.

18-year-old African-American male

Another reason why you should get tested is 'cause there's OraSure. It's easier than needles.

15-year-old Latina

I don't mind needles, but it would be more comfortable with a saliva test.

19-year-old untested African-American male

The saliva test was easy, but I would have come in anyway. I'm kind of glad it was this easy. It didn't take that much time. But it didn't really matter to me whether he took the needle or not.

18-year-old African-American male

I could have got a test free from my doctor, but did I really want him to know? So I just went to the clinic and got it done. I wasn't prepared for the questions he would ask me. If I asked him for the HIV test, he would probably go, "Why?" and ask me a whole series of questions.

Gay African-American male

Overall, most of the teens who had blood taken for HIV tests were likely to be at least tolerant of the procedure, often saying that they didn't particularly mind needles. A sizable minority of these tested teens, however, were quite vocal about their dislike of needles, even though it had not deterred them from being tested. "I'm scared of needles. I've been scared of them since I was little," said a 16-year-old Latino.

The availability of the oral HIV test, OraSure, "made it easy" for several teens who were tested by this method. Most tested teens, however, said having blood drawn for an HIV test was not of particular concern for them, but said they would have opted for the oral test had it been available or offered to them.

One 16-year-old African-American, for example, said she would be "more likely to get tested [again] if I could have the saliva test." As one teen, when informed during the interview about the availability of oral tests, commented: "If I'd known ahead of time that there was more than one method to be tested for AIDS, I'd have taken it."

One young Latino wryly noted that an oral test would have alleviated the need for the tell-tale Band-Aid that revealed to his peers, his family and the world that he had taken a blood test. While oral tests were clearly the preferred alternative for teens, it should be noted that a few teens believed a blood test might be the more accurate or reliable choice for HIV testing.

For a very few teens, the association of needles with HIV transmission, coupled with stories about experiences with syringes in clinics, compounded their fears of the testing process. One 17-year-old African-American said she feared needles, "because there was a lady who was pregnant and they stuck a needle in her stomach and it broke. Some doctors don't change their needles. This doctor had a needle laying out on the table. It could get germs or something."

PRE-TEST COUNSELING

Interviews with tested teens suggest that often well-intentioned questions, comments and conversations by health professionals prior to and during HIV testing were sometimes misperceived by teens, leading in some cases to a sense that they were being pandered to and serving to heighten rather than reduce their anxiety over the possibility of a positive test result.

Teens regularly commented on the amount of paperwork involved with HIV testing and on the number and types of

They're not going to give you the test if you're going to have a negative reaction to it [emotionally].

African-American male

Do I answer truthfully, or do I beat around the bush? I've noticed that sometimes when you come out to a doctor, they treat you kind of different.

Gay African-American male

When you're gay, and if you think there are two different tests, you think, "What if I lied?" A friend told [the doctor] he had straight sex, and the results came back negative, so he asked, "Is that accurate?"

Gay Latino teen

They didn't really talk. They told me I could take free condoms and they were telling me about safe sex, "You have to be careful out there." They could have went into more detail, told me about other STDs and stuff.

18-year-old African-American male

He asked me if I had any questions about HIV and whatever like that, but I don't really have any questions. Throughout most of my school career, they talked about it to us, so I basically know the consequences.

18-year-old African-American male

questions they were asked, questions clearly designed to aid healthcare professionals in assessing risk.

For some teens these questions seemed unnecessary and arbitrary, while for others, they were inordinately personal. One African-American young man said of these pre-test questions:

They're too personal. "Who did you have sex with?" All that. "What age were you?" They stop turning into a doctor and they want to become a counselor and shit and help you with your problems.

In addition, questions intended to gauge teens' psychological strength and ascertain whether they have an emotional support network in place were perceived by some as deterrents to their testing decisions. As another African-American young man said:

They ask you, "If the test comes back positive, what are you going to do?" If you say you're going to kill yourself, they're not going to let you do that, so they won't give you the test.

A discussion among several gay African-American young men in one focus group session also demonstrated the awkwardness young gay teens said they felt when subjected to a battery of questions about their sexual behavior:

It's hard when you have a doctor that automatically assumes that you're straight. "Did you have sex with her?" And you're sort of embarrassed to say, "Well, it was a him."

Notably, a few gay teens indicated that they had believed "different" or "stronger" HIV tests were used for gay or bisexual people. As one gay African-American teen said, "I wasn't so educated about STDs and HIV, so I thought that if I lied [and didn't say I was gay], then I would get the wrong test and that it would have some type of effect on the results of the test."

For most of these tested teens, pre-test counseling was limited to explanations of the HIV testing procedure, how they would be given test results and the availability of counseling should they test positive. Importantly, however, comments about the availability of counseling should a teen prove to be HIV-positive often served only to heighten teen anxiety by focusing their attention on the possibility of a positive result.

I was given an HIV test when I became pregnant. They said I would receive counseling and everything was confidential. I could seek counseling if I was positive. I had to have counseling whether I was positive or not because they said it could show up later.

19-year-old African-American female

The guy that did my test, he was a doctor. He just kept talking to me the whole time, and when he asked me my questions, he said I had nothing to worry about. He was a nice guy.

17-year-old Latina

I took the blood test. The doctor said, "I really doubt it, but let's make sure."

18-year-old Latina

In speaking about the pre-test discussion she had with a clinic staff member, a 17-year-old African-American woman remarked:

They was saying there could be counseling, go into a program with people that has HIV, so I could feel comfortable and get along with them.

Relating one extreme case of anxiety-producing pre-test conversations with medical professionals, a gay Latino teen said:

It was just a regular check up and as soon as I told them I was gay, they were like, "Well, you should really get checked out 'cause most likely you're HIV-positive or all this stuff. [It made me feel] like crap....They had basically convinced me that I was HIV-positive. I was like suicidal at that point. I didn't even want to know. When I got there [for the results], he was like, "Okay, it's negative," and I was so relieved, but I felt like they were such assholes for doing that to me.

In contrast, several young people said their anxiety was in fact alleviated somewhat because of conversations medical personal had with them during or immediately before testing. These conversations, including such simple statements from medical professionals as, "I'm sure everything is okay," served to reassure teens. One 17-year-old Latina talked about the importance of the conversation she had with her doctor before being tested:

He said that he knew that I was scared. He told me not to worry. That even if things came back the way I don't expect them to, that doesn't mean I'm going to die. I was nervous. I kept thinking, "I'm so young. What if they tell me I can't have kids because of the illness? What if I die?" But after he explained a lot to me, I knew that even if I did have HIV, it didn't mean that I would necessarily die. I knew beforehand, but I guess I wanted to hear it from a professional.

Along the same lines, one African-American young man suggested that he would have liked the doctor to "tell me my options, like what could I do if it comes back positive, how should I tell my parents. Stuff like that."

I thought about it a lot. It's impossible [not to while you're waiting for results]. This is your life you're talking about here. You can try to avoid it, you can do everything to keep yourself occupied, but there's no way you can keep it out of your mind.

17-year-old Latino

I thought about it every once in a while. But I was pretty sure I was going to be negative, I hadn't been exposed to anything. So it was just a matter of, you know, kind of anxiousness. I wanted to get the results back now. Just almost to have it down in writing.

Latino teen

I was trying not to think about it, because I was [trying] to think positively.

19-year-old African-American female

I wasn't scared to take the test, but I was scared to get the results. I was *very* scared. I was imagining if I had it, it's the end of my life.

19-year-old bisexual African-American female

I won't take it again. When you're waiting for the results, it's scary. The worst three days of my life. I would have died right there.

18-year-old Latina

You run through all these scenarios in your head: "Will I be lonely for the rest of my life." You wake up in the middle of the night sweating and, "Wait a minute! Sweating is part of it." I dying *now!*

Gay African-American male

THE WAITING PERIOD

One common and negative thread courses throughout teen experiences with HIV testing: the waiting period for test results. The waiting period, in the words of one teen is like "experiencing your own death." As if in counterpoint, however, a few teens, while still reporting a great deal of turmoil during the period before receiving results, said the waiting period had been made more tolerable by the pre-test counseling they had received.

Teens who maintained that the waiting period for test results did not cause them particular concern often revealed that their attitudes resulted from a general feeling of confidence that they were HIV-negative, of submission to fate or a history of multiple testing experiences that made their uneasiness at least somewhat familiar and expected. One 18-year-old African-American, who indicated he had unprotected sex "about 10% of the time," said of the waiting period:

I'm not going to lose sleep over it. Same old, same old. I expect the results to be negative...I'm not the type of person to sit and really stress. I feel that everything is done for a reason on this earth. God makes everything done for a reason.

In contrast, however, the vast majority of tested teens described the waiting period with words like "terrifying" or "the worst experience of my life." Not only was this attitude expressed by teens who sought testing because of fears of possible exposure, but also by those who were more secure about the likelihood of their negative status. Importantly, for a few of these teens, the anxiety produced during the waiting period convinced them never to be tested again. Indeed, others who had been tested more than once said the waiting period was not easier for them the second time.

While the decision to be tested was difficult enough for many of these teens whether or not they expected negative results, the waiting period brought on myriad "what-if" scenarios and guilt. As a gay Latino teen said of waiting for test results:

It was like the most terrifying three weeks ever. I had insomnia. You think about all these things. You know, at night I'd think about how I was going to die, how I had to tell my family, how long I'm going to live, how I'm going to look when the disease really hits me. Then I was feeling guilty, like I really messed up.

When I got off the bus [to pick up my results], I was nervous. I was going to go back home. But I went in. I just wanted to know the results.

18-year-old African-American male

They called and told me I was negative. I had some drinks and smoked some weed. But the two days it took for them to do it, I was stressing like a motherfucker.

African-American male

After my doctor gave me my results, she told me so much more. She gave me a lot of information, so if you're negative, you know what you have to do to live your life and stay negative. And if you're positive, you know what you have to do to take care of yourself.

Gay Latino teen

I had to go back in two weeks. I asked, "did you call? Did I miss the call or something?"

African-American male

With the added imperative to keep HIV testing confidential, one 19-year-old bi-sexual African-American woman in fact suggested: "During that time, waiting for the results, if they had counseling, just to talk about your fears, then it would have been easier, because I would have been able to express my concerns to somebody."

Despite their apprehension, and often because of it, nearly all of those interviewed said they were extremely eager to receive their test results: from the Latina whose doctor personally delivered results to her at school to put an end to her multiple daily calls to his office, to the African-American teen who said his efforts to get his results from his doctor meant "I was beeping her ass nonstop. Call me back!"

RECEIVING RESULTS

Although the majority of teens reported that they had been told that their HIV test results would be available to them in two weeks, teens variously said that they had been told the waiting period would be from as few as "two or three days" to as much as six weeks. Several teens also said, with obvious frustration, that they had nervously arrived at clinics to receive their results at the appointed time, only to be told by staff that there was a delay, they would have to return later, or that the clinic "couldn't find" their results or had "lost them."

Teens also reported little consistency in the methods by which their test results were delivered. Most frequently, teens were told when to call the clinic or testing site to confirm that their results were available and then to make an appointment to talk about their results. Nearly as often, and usually with teen-oriented health clinics and mobile outreach vans, teens were told in advance when and where to come to pick up their results.

One 18-year-old African-American described the variety of his experiences learning of test results this way:

[Staff at the other clinic] didn't come in and say, "You got it" or "You don't got it." They say, "We'll call you or notify you by mail if you got something. If you don't, you're not going to hear from us." Here [at a teen clinic], they say come back in two or three weeks for your results.

In cases when testing was done anonymously or, in a few cases, at mobile testing vans, teens reported that they had been given a code number and instructed to call for their

results after a specified period. In a very few instances, teens said that their doctors had “called the house” to give them what proved to be negative results, or that they had been told someone would call them “confidentially, if anything was wrong.”

In one anomalous incident, a young Latina reported that she had been HIV tested as a requirement for her parents’ health insurance renewal and only learned that she was HIV-negative when her mother told her that their policy application had been accepted.

Only in rare instances did teens indicate that they delayed or avoided picking up their test results. One gay Latino teen, who has since been tested multiple times, explained why he had not returned for his results after being initially tested at a mobile unit:

They tell you hat you don’t have to pick up your results if you don’t want to. I didn’t go back, because I figured it would be the best thing for me to do to get it from my doctor. I didn’t know the people in the [van] and it was better for me to get my results from someone I trusted and knew who I was.

Another gay African-American teen commented on his negative reaction to the air of confidentiality and emotional neutrality that a clinic staff member assumed while delivering his test results:

When the lady came in, she scared the shit out of me. She had a solemn look on her face. I just knew I got it because of the way she looked. She asked me a couple of questions and said, “Just follow me.” She said, “I’ve got news to tell you, but I have to tell you in a room.” Now I know for a fact it’s all over. Then she goes, “It’s negative.” All that drama.

Indeed, for many teens, getting their test results was the climax of the “what-if” drama that had been playing out in their minds for days or weeks. In many cases, teens described or alluded to intense physical reactions in anticipation of and as test results were being delivered. As one African-American young man said:

It’s not that easy. They stick you with that needle, that might [take] three seconds. But whatever comes, that couple of days you’re waiting for the test results...and then [when you’re getting your results], your heart is beating FAST.

It eases your mind. Personally, I was a ‘ho. It takes that stress off you.
Gay African-American male

[Negative results] make you change your behavior for a minute. But then you're about to get some and you don't think about it.

African-American male

I not going to get another test, because I'm going to be so safe.

19-year-old African-American female

When you see [you're negative], you feel like you're one of the few. You're special. It's the relief. You don't got to worry about it no more. You feel safer, but you still gonna worry about it because you're still having sex.

African-American male

I keep getting tested because I keep sleeping around. I use condoms all the time now.

18-year-old African-American male

I'll probably get tested again when I go for my OB/GYN this year. A full physical....Testing is a positive thing. You just don't talk about it. It's not casual, it's just, "I'm going to the doctor." That's your business, it's not anybody else's. I'm pretty sure that a lot of teens who care about themselves would do the same thing I did.

17-year-old African-American female

I think I'm more likely to get tested again, because...I would feel more comfortable because I know where to go and what to expect. There would be no surprises.

18-year-old African-American male

Nearly without exception, teens reported that the impact of receiving negative results was an immediate determination to regularly practice safer sex. Raising their hands as if taking an oath, African-American young men in one focus group session repeated the promise they had made to themselves: "I swear I'll never have raw sex again." But as one acknowledged, "I think I broke my promise the next day." Nevertheless, many teens told us that they had indeed altered their behavior as a result of having been HIV tested and others said they felt that being HIV tested had confirmed to them that what they were doing was right.

ATTITUDES TOWARD RE-TESTING

The vast majority of tested teens indicated a general willingness to be HIV tested again; in fact, many had already been tested several times. Still, three of the 50 tested teens interviewed were adamant that they would never again subject themselves to an HIV test because of the terror they had experienced while waiting for their results. Moreover, the anxiety all these teens felt during the days or weeks between testing and receiving their results clearly complicates their decisions to be tested again.

The negative test results teens received frequently served as confirmation that they had indeed been "responsible." Negative results were seen as verification that they had behaved correctly. As a consequence some viewed the need to be tested again with less urgency, particularly when waiting for another, presumably negative, test result might again subject them to unnecessary anxiety. Often teens said they would be willing to be tested again only, "If I feel the need for it." One African-American teen explained his attitude about being HIV tested again this way:

It's going to be a little bit easier [to get tested again], but that stress on your head and all that other junk is still going to be up there.

In addition, HIV testing experiences as related by the teens in this study vary widely and have considerable impact on teens attitudes toward being retested. While many teens who reported generally positive attitudes toward the testing experience said they would opt to be tested again at the same facility, others viewed the centers at which they had been tested with varying degrees of negativity and said they would seek out other testing sites if they felt the need to be tested again. These reports of testing experiences, both

A clean place where everybody's all nicely in uniform. They look decent, don't have a bad attitude. They attend to you like you're supposed to be treated. They'll treat you nice, not always being like, "Why are you doing this in the first place?"

17-year-old Latina

I wouldn't go to a free clinic over there. It's just dirty over there. There was garbage and stuff on the walls, dust and stuff. It was just filthy in there. Back in the waiting room, it smelled like shit in there. Just garbage everywhere, everybody bitching at you behind the counter. I'd rather pay a hundred dollars to get it done.

18-year-old untested Latino

It was isolated, very quiet, very clean. A very nice, clean place. They were very friendly.

17-year-old Latina

I'd look for a good environment. Confidentiality. I wouldn't pick a popular place. It would be farther away from home. I'd drive or take public transportation.

19-year-old untested African-American male

positive and negative, serve by implication to define what teens themselves perceive to be "youth-friendly" testing sites.

YOUTH-FRIENDLY TESTING SITES

Throughout these interviews and in a variety of contexts, teens revealed both directly and indirectly the factors, environment and attitudes that they regard as contributing to HIV testing sites that they perceive, or would be more likely to perceive, as "youth friendly."

- **Professionalism and Respect.** Minimally, teens expect to be treated professionally and with respect by clinical and support staff. Despite their age, or perhaps because of it, they see themselves as responsible, sexually-experienced individuals who deserve to be treated with courtesy and as mature adults.
- **A Clinical Environment.** Teens fully expect that clinics, HIV testing sites and teen health centers will be clean, neat and well-organized, with an air of clinical professionalism that reassures them that they are not receiving less than high-quality care because of their age or lack of resources.
- **Full-Service Teen Health Centers.** When a wide range of health related services and testing is available at a center, teens know that others who might see them will never know why they are there; their confidentiality is protected.
- **Free or Low-Cost Services.** Because teens lack financial resources or health insurance or because of their need to avoid involving parents in sensitive healthcare issues, cost is a prime consideration among teens in their search for services.
- **Testing Options.** Offering the option of taking either a blood or oral HIV test increases the likelihood that teens will return for additional tests when they feel the need.

- **Rapid Testing.** Although “rapid testing” was not something teens in this study talked about or directly expressed an awareness of or a need for, we believe access to “rapid testing” would have a motivating impact on teens’ HIV testing decisions, especially given their negative attitudes toward the test result waiting period.
- **Access.** Convenient or, in the case of mobile testing vans, immediate access to facilities that take advantage of teens often impulsive HIV testing decisions.
- **Pre-Test Counseling.** Pre-test counseling that reinforces the positive benefits of their decisions to be tested and helps to relieve the inevitable anxiety they will feel as they wait for their results.
- **A “Cheerful” Environment.** Although teens expect testing sites to project a professional, clinical air, that does not mean they want sites to be dour or depressing.
- **Fewer Questions and Paperwork.** Reducing the number of questions and paperwork, or at least explaining the need for them, alleviates teens obvious impatience. For gay and bi-sexual youth, it is particularly annoying when standard questions about their sexual behavior assume heterosexuality.

One 17-year-old woman, a former substance abuser who had been tested multiple times, spoke at length of the multitude of factors that have influenced her decision to avoid a particular clinic in favor of others with more teen-focused environments and staff:

It was like an office with a lot of boxes full of condoms on a bookshelf and all the papers and stuff on the desk. She pulled stuff out of the drawers and she took my blood right there in the office, sitting in the chair. It wasn't comfortable, it wasn't like a lab environment, a doctor's office environment. There were all kinds of people and age groups. Every time I go to that clinic...it's just not a comfortable feeling. The place is kind of dead. It makes you think about death when you walk in the door.

I feel like, personally, when I go to the doctor's office, and I see bright colors and smiling faces and magazines and people who are happy and cheerful, everything's clean and nice and neat, it makes me feel good. When I go somewhere and everything's piled up clutter, and you're walking into a dump, you don't feel really comfortable.

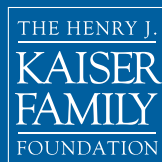
In contrast, this same young woman spoke of the teen clinic she now frequents:

The staff, the nurses were just outstanding for me with their attitude. They try to reach out and touch everybody, 'cause a lot of these kids come from the streets....They try to do their best to touch and comfort everybody, show somebody out there cares...And make them relax, and try to make them see that it's not the end of the world if they do have it.

It is our hope that this qualitative research, by articulating the voices of those teens most at risk for HIV, by probing their perceptions, concerns and fears about HIV and HIV testing, as well as their struggles, resilience and confidence, will assist healthcare professionals, program developers, policy makers and youth outreach specialists in designing messages and programs that offer better and more effective HIV testing options for teens.

- 1 Centers for Disease Control and Prevention, Young People at Risk – Epidemic Shifts Further Toward Young Women and Minorities, September 1998.
- 2 Centers for Disease Control and Prevention, CDC Facts: Adolescents and HIV/AIDS, March 1998.
- 3 Centers for Disease Control and Prevention, HIV/AIDS Surveillance Report, 1998 Year-end edition, Vol. 10, No. 2.
- 4 Centers for Disease Control and Prevention, “Diagnosis and Reporting of HIV and AIDS in States with Integrated HIV and AIDS Surveillance—United States, January 1994-June 1997”, Morbidity and Mortality Weekly Report, Vol. 47, No. 15, April 1998.
- 5 Kaiser Family Foundation/MTV/Teen People, “What Teens Know and Don’t (But Should) About Sexually Transmitted Diseases: A National Survey of 15 to 17 Year-olds,” March 1999.
- 6 Kaiser Family Foundation, World AIDS Day Teen Survey, November 1998.
- 7 Kaiser Family Foundation/MTV/Teen People Survey.

The Kaiser Family Foundation, based in Menlo Park, California, is a nonprofit, independent national health care philanthropy and is not associated with Kaiser Permanente or Kaiser Industries.



The Henry J. Kaiser Family Foundation

2400 Sand Hill Road
Menlo Park, CA 94025

650-854-9400 Facsimile: 650-854-4800

Washington Office

1450 G Street, NW, Suite 250
Washington, D.C. 20005

202-347-5270 Facsimile: 202-347-5274

<http://www.kff.org>

98-1926A

Additional free copies of this publication (#1492) are available by calling The Henry J. Kaiser Family Foundation's publication request line at 1-800-656-4533 or download this publication from our website at www.kff.org.