

## Research Team

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**P**roject Access is a qualitative study of barriers to HIV counseling and testing, and the personal HIV prevention strategies of drug users.

## Main Findings

- Drug users' risk behavior was not directly related to the number of times they had previously tested for HIV.
- Personal prevention strategies and HIV testing patterns are shaped by public health messages, institutional practices, and the concrete realities of living and surviving in impoverished communities.
- Many low-income drug users approach HIV as a chronic illness, one of many life-threatening diseases facing their communities. HIV infection was seen as random and unpredictable, the virus was believed to lay dormant and completely undetectable within the body for years, and routine screening (HIV testing) was believed to be a primary means of managing HIV.
- Race, class, and gender infect individuals' perceptions, their responses to the threat of HIV, and their motivations for HIV testing.
- Health and social service referrals can play an important role in linking these populations to needed services.

## Why This Project?

Project Access was conducted in three San Francisco Bay Area counties: Alameda, Contra Costa, and San Mateo. These counties were selected on the basis of high rates of HIV among injection drug users (IDUs), the presence of special outreach efforts to reach active drug users with HIV counseling and testing (C&T), and the relative lack of HIV research in these areas.

Project Access utilizes community-based, qualitative approaches to understand public health and social problems and identify solutions to address them. Being community-based means that the study is conducted in an everyday setting that participants frequent, be it a needle exchange site, health department outreach and testing van, (prostitution) stroll area, shooting gallery, or crack house. Qualitative methods facilitate the contextualizing of problems, allow flexibility and

responsiveness to emerging issues, and are appropriate when seeking to understand local meanings, processes, and changing conditions.

The aim of Project Access was to explore barriers to HIV C&T utilization and personal prevention strategies within a relatively under-researched, isolated group of drug users. The larger purpose of this project is to enhance access to and delivery of C&T and other prevention services for drug users. Project Access used research findings to provide technical assistance (TA) to service providers and county and state agencies to develop and implement effective HIV prevention messages, protocols, and policies tailored to drug users.

## Methods

## Recruitment/Site Selection

Local community health outreach workers recruited a convenience sample of drug users from various venues, including needle exchange sites, harm reduction centers, drug treatment programs, mobile health or HIV testing vans, and shooting galleries. These were located in neighborhoods typically characterized by substandard housing, poor access to commercial development, and active drug markets. Venues were selected after Project Access conducted formative research<sup>1</sup> with providers serving high-risk drug users in Alameda, Contra Costa, and San Mateo Counties. The sites represented the types of programs currently serving drug-using populations in all three counties. All participants provided informed consent and were reimbursed \$20 for their participation in the study.

## Data Collection

One hundred and eighty-seven (187) drug users were interviewed in street and community settings. Interviews were conducted from July 1997 through January 1999. Each interview consisted of two primary components: a qualitative guide and a brief quantitative survey. The instruments developed were based on research questions and issues identified through interviews with service providers and then revised through pilot testing. Based on the analysis of barriers to C&T utilization, the instruments were revised substantially to

address newly emerging questions and issues (e.g., personal HIV prevention efforts as related to daily life context; the context of sexual and drug-related risks). The qualitative guide for this study was used to elicit narratives on topics including: a) HIV testing experiences; b) sex and drug risk for HIV; c) C&T motivations, frequency, and satisfaction; and d) use of referrals. The quantitative survey was used to collect: a) demographic information; b) sex and drug risk histories; c) testing history and experiences; d) self-reported HIV status; and e) referral and resource utilization. On average, the interview took approximately one hour to complete. Interviews were tape recorded and transcribed. No identifying information was collected.

*"... to me, [HIV testing] is like getting a pelvic test. This is part of your life. You must do this to maintain your life. Y'know what I'm saying? Because you never know what's gonna happen."*

## Dissemination and Technical Assistance

Project Access has been active in disseminating research findings<sup>1,2</sup> and providing TA to service agencies.

- Staff have presented at State-hosted meetings bringing together coordinators of HIV street outreach programs from all over California.
- Staff have provided various forms of TA to service providers. For example, staff conducted a presentation and training on field-based testing for a county that was soon to implement this for the first time.
- Project Access has ongoing involvement in the greater Bay Area meetings of HIV C&T county coordinators aimed at problem solving and strategic planning.
- Project Access hosted an HIV Testing Roundtable to which coordinators from three surrounding counties and their contractors from community-based organizations (CBOs) were invited. This roundtable was structured around issues identified by Project Access's provider data and through consultation with the local health department HIV C&T coordinators. An agenda was created to allow people from each of the counties to talk in detail about their successes and difficulties, share experiences, and problem-solve together while beginning to utilize new technologies, particularly OraSure and field testing.
- Project Access held a follow-up meeting that included staff from the Office of AIDS as well as local county coordinators. This meeting of stakeholders clarified the intention of state procedures and protocols, and pointed out directions for future programming and protocols. Participants' evaluations showed a high level of satisfaction with this second roundtable discussion.

## Selected Key Findings

Who was interviewed?

This sample is comprised of low-income drug users and predominantly people of color.

- Women and men were similarly represented; the majority (62%) identified as African American; Whites comprised 31%, Latinos 11%, and Native Americans 7%.\*
  - Slightly more than one-fourth of the sample was currently homeless.
  - The most frequently cited sources of income were a job or business (58.3%), friends/family (54.2%), and government assistance programs (53.3%) such as AFDC, GA, or SSI. After this, drug-related income and panhandling were equally cited by 28.3%, and boosting (shoplifting) and sex work were similarly cited by more than one-tenth of the sample.
  - Crack cocaine and heroin were the most commonly used drugs (reported by 33% for each), after alcohol (42%).
  - Women and men were equally sexually active (totaling 72% of the sample), although women had on average more sex partners. One-fourth of the women reported trading sex.
  - Lifetime number of HIV tests ranged from 0 to 40, with a median of four.
- \* *NOTE: Some participants identified as belonging to more than one ethnic group.*

What are the risk behaviors, and how are these related to HIV testing?

To answer this, we conducted a sub-analysis in which participants were classified according to one of four typologies of recent injection-related and sexual risk behaviors (high injection-related/high sexual risk; high injection-related/low sexual risk; low injection-related/high sexual risk; and low injection-related/low sexual risk). High injection-related risk was defined as any sharing of needles, cookers, cottons, or water, and/or frontloading, backloading, piggy-backing, or using more than one syringe to mix or divide drugs. High sexual risk was defined as any unprotected vaginal or anal sex. We found:

- More than one-fourth (28.2%) of participants had high injection-related risk; more than half (53.8%) had high sexual risk.
- The largest proportion of participants (38.5%) fell in the low injection/high sexual risk category, followed by one third (33.3%) in the low injection/low sexual risk category; 15.4% fell in the high injection/high sexual risk group; and 12.8% in the high injection-related/low sexual risk group.
- Individuals view drug use as their primary risk.

- There was no direct correlation between the number of HIV tests and risk type.

**Comment:** The analysis shows that this sample of drug users had greater risk associated with sexual activities than with drug use. This is illustrated in the following example: One study participant who operated a shooting gallery maintained strict rules prohibiting the sharing of needles in this setting. By contrast, he used condoms with his girlfriend (a sex worker) roughly one-fourth of the time, and never with his wife. The greater sexual risk observed in this sample may be due to effective drug-related HIV prevention efforts and/or the greater salience of drug-related risk as compared to sexual risk. Additionally, complex cultural pressures may make it difficult to alter sexual practices.<sup>3</sup>

High frequency testers (i.e., six or more lifetime HIV tests) included those with low behavioral risk as well as those with high risk. Similarly, low-frequency testers included individuals with high as well as low behavioral risk. This was a surprising finding; it raised questions about the meaning and logic surrounding repeat HIV testing.

Why do people test so often? <sup>6</sup>

- HIV infection is viewed as random and unpredictable. While many drug users had similar risk behavior, some became infected while others did not.
- HIV was believed to be dormant and undetectable to tests for 10 years or more. Thus it was felt HIV might “pop up” at any time, despite previous negative test results.

A man commented, “*So, it was just basically nerve-racking. And still is today, cuz I don’t know when it might pop up. But then when [the HIV test] came back negative, I’m like aw, man. But then they say it can sit in your system for a long time. Five years or more.*”

A woman observed, “*... and I think back on it ... and it’s just like, well I better go check it out [get an HIV test], check myself out, keep myself alert of ... that eight-year period, I am still in that eight-year period. I dunno if I can have a flare-up on it or not...*”

- Routine HIV testing, regardless of current risk behavior, was accepted as part of normal self-care, like a Pap smear or diabetes screening. As one woman commented, “*... to me, [HIV testing] is like getting a pelvic test. This is part of your life. You must do this to maintain your life. Y’know what I’m saying? Because you never know what’s gonna happen.*”
- Institutions with which IDUs interact (such as prisons, hospital emergency rooms, drug

treatment programs, and prenatal care programs) inadvertently encourage these perceptions and practices by advocating routine HIV testing for IDUs.

**Comment:** The perceptions of HIV and testing among this sample of drug users reflect faulty information (e.g., regarding the dormancy of HIV) as well as institutional encouragement. Together, these perceptions and experiences of the seemingly random nature of HIV infection, its prolonged dormancy, and institutional testing policies create a context in which routine HIV testing is a sensible means to manage the threat of HIV, similar to a chronic illness.

How do HIV testing and perspectives on HIV among drug users relate to gender, race, and class?

Motivations for testing were gendered: compared to men, women placed less emphasis on incentives or compensation for testing, and more on concerns for family or significant others.<sup>5</sup>

- Low-income African American drug users saw HIV as part of larger problems plaguing their communities, such as the lack of societal concern for impoverished urban areas and the discontinuation of programs and services in poor communities.
- Low-income drug users are afraid and want to protect themselves, but may also become desensitized to yet another “killer” in their communities. One man’s remarks sum this up: “*In the old days, when a person dies, it was a great phenomenon. Everybody mourned, the whole town. As far as it go, over in San Francisco. Cuz it wasn’t as much killin’ like it is now. Now I feel the reason why people’s not trippin’ off and takin’ them strong considerations [HIV prevention measures] is because of the simple fact, they senses have got dull to the fact that people is dyin’ like they’re dyin’. It’s just no big ordeal anymore. ... For instance, three of my homeboys just got killed; or two of ‘em, but one is strugglin’ for his life. Little youngsters. It’s nothin’ ... fuck it, you gonna die, man. Everybody’s afraid. I don’t give a damn, man. We livin’ in hell anyway.*”

**Comment:** Many participants were from low-income communities of color that are inundated with chronic health (and life) threats. Gender, race, and class affect drug users’ perspectives on HIV,<sup>6</sup> their responses to the threat of HIV,<sup>3</sup> and their motivations for HIV testing.<sup>5,6</sup>

What is the role of referrals through C&T? <sup>7</sup>

- Referrals can serve an important role in linking marginalized populations with needed services.

*Low-income drug users are afraid and want to protect themselves, but may also become desensitized to yet another “killer” in their communities.*

- Drug users who receive health and social service referrals find these useful.
- Provision of service referrals varies from counselor to counselor.
- Whether referrals are useful and utilized is affected by: the individual's serostatus, the point during which referrals are given in the C&T process, and an individual's competing needs and concerns.

**Comment:** The referral process should be tailored to the circumstances of the individual.

## References and Additional Reading

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7. Vu, C. HIV Counseling and Testing Referrals: A Dialogue with Clients (Thesis, May 2000, Yale University).

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## Recommendations

### Policy Recommendations

- Improve institutional testing programs (prisons, hospitals, drug treatment centers, pre-natal and Women, Infants, and Children's programs). Many individuals receive their initial HIV education and testing through these programs and have ongoing contact with these institutions.
- Improve access to comprehensive services, especially residential drug treatment and methadone maintenance programs, housing, and economic development programs. These programs begin to address some of the larger structural issues that place individuals at risk.
- Encourage collaboration between service providers and county agencies. Increase opportunities for different "categories" of providers (e.g., housing, drug treatment, economic development) to work with HIV prevention providers through forums, roundtables, the HIV Prevention Planning Council and Ryan White planning processes, and joint funding opportunities.
- Remove punitive drug control policies, and encourage local needle exchange, sale of over-the-counter syringes at pharmacies, and high thresholds for receiving services.

### For Counselors

- Provide referrals during pre-test counseling.
- Review referrals at results.
- Clarify six-month window. Regular testing can be an effective strategy to keep individuals engaged in and thinking about HIV prevention, but the fact that the test is effective in detecting virus contracted anytime up to six months prior to the test should be emphasized.
- Provide additional counseling to repeat testers in order to: 1) relay accurate information; 2) discuss underlying anxiety/ reason for repeat testing; and 3) address current prevention needs.
- Talk about sex. Counseling with active drug users should include risk reduction planning related to sexual behavior. While many drug users may be concerned about their drug-related risk, they may in fact have greater sexual risk, which is not often addressed.
- Incentives are an effective means of getting high-risk individuals into C&T. The process of testing, even if motivated by incentives, is beneficial.
- Confidentiality! Confidentiality! Confidentiality!: Repeatedly explain the difference between confidential and anonymous testing.

## Materials Available

Information and materials on Project Access are available at the following web site:  
[www.caps.ucsf.edu/capsweb/projects/accessindex.html](http://www.caps.ucsf.edu/capsweb/projects/accessindex.html)

Additionally, Project Access will be happy to share material. Write to Moher Downing at AIDS Research Institute, Center for AIDS Prevention Studies, University of California, San Francisco, 74 New Montgomery, Suite 420, San Francisco, CA 94105, or email [mormag@itsa.ucsf.edu](mailto:mormag@itsa.ucsf.edu).