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## Formative Research

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**W**hen planning a new intervention, agencies often have an idea of what to do, but need to understand the best way to do it. And when a new intervention is designed for a relatively new population, they need to know if what they've been doing in other communities will work for them. That's where formative research fits in.

Formative research looks at the community in which an agency is situated, and helps agencies understand the interests, attributes and needs of populations and persons in their community. Formative research is research that occurs before a program is designed and implemented or while a program is being conducted. Formative research can help:

- ▶ Understand populations in need of services
- ▶ Create programs that are specific to the needs of those populations
- ▶ Ensure programs are acceptable to clients and feasible before launching
- ▶ Improve the relationship between clients and agencies

Because HIV prevention has traditionally focused on HIV negative persons, many prevention workers may not be familiar with the needs of persons with HIV, and healthcare and social service providers may not be familiar with prevention. The worlds of care and prevention are often far apart, with separate offices, different training and background for workers and even distinct pots of money for funding. Agencies need to know about many different aspects of a person with HIV's life in order to design effective PwP programs.

Conducting formative research doesn't have to be daunting. In fact, it can be quite easy. There are several quick and practical ways to collect information:

- ▶ Focus groups
- ▶ Key informant interviews
- ▶ Surveys
- ▶ Field notes

For PwP programs, some important people to talk to are: persons with HIV, clinicians serving them, social workers or case managers, partners or families of persons with HIV and HIV testing counselors.

It is always important to keep an open mind. Research results often confirm exactly what you thought, and just as often tell you something you never realized. And people are usually happy to be asked their opinion, to feel as if they are contributing to their own services. This is especially true for the stigmatized and vulnerable populations to which persons of color with HIV often belong.

### ● ● ● Reality check

Many agencies do not have the resources to conduct formative research and few funders will support research in an agency. This shouldn't stop agencies from providing programs, however. We know enough about the needs and concerns of persons with HIV to start good, solid programs. We can learn from research conducted with similar communities that is often relevant to our own.

### ● ● ● Examples of formative research

When looking at formative research results with varying populations of persons of color with HIV, certain issues come to the forefront and are worth noting. Obviously, not all of these will be concerns for every community across California and the US, but they can be used as starting points for programs:

- ▶ For agencies that will be conducting their own formative research, these can inform the questions asked during interviews or focus groups, or suggest key informant interviews.
- ▶ For agencies that can't conduct formative research, these findings can inform skills building activities or be used as topics for discussion in support groups or counseling.

The following formative research findings about persons with HIV are taken from APC's P3 Initiative as well as other formative research projects in California. These findings may not be applicable to all communities as they are from small research studies within one agency. The communities represented in these findings are:

- ▶ African American sex workers and substance users in Alameda County, CA
- ▶ African American MSM and gay men in Alameda County, CA
- ▶ Injecting drug users in the San Francisco Bay Area, CA
- ▶ African American and Latina heterosexual women in Los Angeles, CA
- ▶ African American and Latino heterosexual men in Los Angeles, CA
- ▶ Spanish-speaking Latino MSM and gay men in Los Angeles, CA
- ▶ Asian and Pacific Islander MSM and gay men and transgenders in San Francisco, CA

**Loneliness is high**

Across populations, persons of color with HIV cited loneliness as a reason for feeling isolated, not being empowered to take care of themselves or engaging in risk behaviors. All of the formative research conducted noted the need to connect with other persons with HIV in their community, whether to socialize, build support or provide peer education.

**Healthcare utilization is high, but barriers continue**

Several research studies found that most persons with HIV currently were in primary care and many were taking HIV medications. However, the quality of care received varied. Maintaining adherence to medication and attending regular follow-up visits with their care providers were still difficult for many persons with HIV. Also, some persons with HIV mentioned fearing the side effects of HIV medications.

**Unemployment and poverty levels are high**

Many of the men with HIV were unemployed or unable to work due to HIV-related disability. For example, among African American and Latino heterosexual men in Los Angeles, CA, over 95% were unemployed; among Asian and Pacific Islander gay men and transgenders, 68% earned less than \$10,000/year.

**Language matters**

Latino/a and Asian and Pacific Islanders with HIV who do not speak English often did not access services or feel comfortable with services if there is not somewhere there who speaks their language. Even bilingual persons who speak English may be better able to express themselves and understand terminology in their native language.

**Condoms are still a problem**

Men with HIV reported many problems with using condoms as barriers to safe sex. These included: feeling like condoms decrease sensitivity, not being able to get or maintain an erection with condoms and feeling like using a condom “spoils the moment.”

**Boredom increases risk**

Due to a lack of employment and high rates of homelessness in two studies, men reported boredom, and having nothing to do and nowhere to go as reasons for having sex.

**Women choose abstinence**

Research with African American and Latina heterosexual women in Los Angeles, CA, found that very few women reported risk behaviors. For most of the women, their method of prevention was abstinence from sex and not sharing needles.

**Homosexuality is stigmatized**

In many communities of color, it was reported that there was still great stigma around homosexuality. Because of this, many men of color with HIV hid their homosexuality.

### HIV diagnosed in hospitals and jails

Some of the persons with HIV did not find out about their status at HIV testing sites. For example, among Latino MSM in Los Angeles, CA, 60% found out they were positive when they went to the hospital for an opportunistic infection. Many IDUs in Alameda County, CA found out they were positive through routine testing while incarcerated.

### Addiction is a barrier to behavior change

Some drug users with HIV reported that drug addiction made it difficult for them to use condoms or stop sharing needles. Many persons with HIV also noted that they had denial, anger and depression about their substance use and abuse.

### Behaviors change comes in stages

Many IDUs with HIV reported increased drug use, isolation, depression, and risk behavior when first diagnosed with HIV. HIV then became a motivating factor to managing their drug use management, taking care of themselves and reducing risk. As HIV became more integrated into their lives, many were able to reframe HIV as a source of strength, education and support.

### Intimacy is key

Many persons of color with HIV reported having a main partner, and many were in long-term relationships. Maintaining intimacy in a relationship often took precedence over using condoms. Some persons with HIV felt pressure from their HIV negative partner to have unprotected sex. Others felt that condom-less or “skin on skin” contact allowed for greater intimacy.

### USE PEERS

It is important to hire interviewers from within the community who can understand and relate to issues brought up during research.

### • • • Best practices

#### Don't be afraid to ask

You may think, “My client won't answer *that*” or “If I ask these questions I'll scare them away.” However, agencies in California conducting formative research with persons with HIV were surprised at how well clients responded to being interviewed. Said one program manager, “Participants were very honest in answering intimate questions and were candid about their family and personal lives.”

#### Use peer interviewers

It is important to hire interviewers from within the community who can understand and relate to the issues brought up.

### Provide incentives

Providing incentives (coupons, transportation, dinner, money) helps to recognize the contributions of clients and ensure participation. One agency mailed out questionnaires and included a dollar bill in each envelope. The response rate was much better than expected, and clients appreciated the gesture.

For more resources on conducting formative research, please see *Chapter 8* and *Good Questions, Better Answers: A Formative Research Handbook for California HIV Prevention Programs*.

[www.caps.ucsf.edu/goodquestions](http://www.caps.ucsf.edu/goodquestions)



Don't forget! Formative research is not only conducted prior to designing an intervention, but also during the intervention (also known as process evaluation). Start with research-based programs and then adjust and revise them as you receive feedback from clients.

The following chapters in the guide list evidence-based components of programs and model programs, all based on research. These models can be adapted to fit your own agency and clients.