



California Collaborations in HIV Prevention Research
Dissemination Project

MODULE 3

**Youth Drug Injectors, Needle Exchange
Use, and HIV Risk in San Francisco and
Santa Cruz**

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California Collaborations in HIV Prevention Research: Dissemination Project

Introduction to the Dissemination Project

To support community-based research efforts in California, the State Office of AIDS (SOA) and the Universitywide AIDS Research Program (UARP) joined forces in 1998 to provide funding for HIV/AIDS community research collaborations. This program is built upon the collaborative research endeavors initiated by UARP in 1995 and community-based research efforts sponsored by SOA. The UARP/SOA initiative fosters partnerships among researchers, community-based AIDS service organizations, and local health departments. As a coordinated response to a statewide public health need, it:

- Provides support for evidence-based planning, design, delivery and evaluation of prevention interventions
- Builds community research capacity
- Disseminates information on HIV/AIDS prevention interventions

UARP and SOA have jointly funded 26 community collaborative HIV/AIDS prevention intervention projects. The *California Collaborations in HIV Prevention Research: Dissemination Project* is designed to disseminate information about these research projects and serve as a resource to be used by local health departments and community-based organizations in support of their work in prevention and evidence-based planning. Each project is presented in a standardized module format that reports on findings from the research and contains resource materials related to training, marketing, research methodologies, data collection, use of findings and collaboration between researchers and providers.

The *Dissemination Project* modules are organized into three sections: Behavioral Risk Research, Intervention Outcome Research and Translation Research. The Behavioral Risk Research section includes projects that focus on the context of the delivery of interventions; **these modules do not evaluate prevention intervention effectiveness.** The Intervention Outcome Research section will provide project findings on effectiveness of specific interventions. The Translation Research section will provide guidelines developed for translation of science-based interventions for use by community service organizations (available in 2005).

SECTION ONE: BEHAVIORAL RISK RESEARCH

Module Focus

Modules in this section highlight information in two areas:

- Behavioral risk patterns among communities heavily impacted by the epidemic
- CBO capacity to implement an evidence-based intervention

These research projects, conducted between 1998 and 2001, collected behavioral risk data on high priority populations of MSM, transgender, IDU, and homeless in San Francisco, Santa Cruz, Los Angeles, and Santa Barbara. One module in this section reports findings from a project that examined CBO capacity and requirements for implementing an evidence-based intervention.

California Collaborations
is a project sponsored by:

Universitywide AIDS
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University of California
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and

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Module Format and Content

The modules cover the following areas of information:

- Research findings and analysis on HIV/AIDS risk behaviors among high-priority populations in California
- Research findings on cultural and organizational context
- Use of findings by the community organization
- Characteristics of successful collaboration between researchers and HIV/AIDS service providers in ASO/CBO settings
- Model needs assessments and evaluation tools
- Resources developed and used during the project (e.g., training, recruitment, and outreach materials)

The four modules in Section One will be available in April 2003 in print format and on the UARP website (<http://uarp.ucop.edu>). Appendix materials include examples of materials used in the research and are downloadable as Microsoft Word documents.

SECTION TWO: INTERVENTION OUTCOME RESEARCH

Module Focus

Modules in this section describe:

- Research findings on interventions tested for effectiveness
- Research, collaboration, and intervention components, along with supporting materials from the research projects

These projects, which began in 1999, focus on evaluations of individual, small-group, and outreach interventions serving MSM, youth, IDU, women, and teen parents. The tested interventions also serve a diverse range of California

populations, including Latino, African American, and Asians/Pacific Islanders.

Module Format and Content

The modules cover the following areas of information:

- Research findings on the outcomes of tested interventions
- Outcome measures
- Tested intervention models
- Research findings and analysis of HIV/AIDS risk behaviors among high-priority populations in California
- Characteristics of successful collaboration between researchers and HIV/AIDS service providers in ASO/CBO settings
- Models and protocols used in evaluation research, including needs assessment and evaluation tools
- Findings on cultural and organizational context
- Use of findings by the community organization
- Resources developed and used during the project

Dissemination of the intervention outcome modules will begin during 2003 in both print format and on the UARP website (<http://uarp.ucop.edu>).

SECTION THREE: TRANSLATION RESEARCH

Module Focus

In 2002, two multisite projects were funded to study the process of translation of evidence-based interventions for use by community service organizations.

Guidance on the Use of Dissemination Modules

PURPOSE

The *Dissemination Project* modules are intended to support evidence-based planning, design, implementation, and evaluation of intervention services. This community collaborative research, funded by the California State Office of AIDS and the Universitywide AIDS Research Program, includes behavioral risk assessments, intervention outcomes, and translation research.

STRATEGY

The modules can be used to integrate findings and research and intervention materials into local planning, design, and delivery of targeted, evidence-based interventions. Research projects are California-specific, and deal with behavioral risks and interventions for populations impacted by the epidemic in California.

USE OF MODULES

Behavioral Risk Modules

- Use data and findings on behavior risks to support targeted planning for prevention interventions targeting similar populations
- Use behavioral risk findings to inform development and/or refinement of programs targeting similar populations.
- Use behavioral risk findings to provide support for existing interventions
- Tailor research instruments and protocols to collect data and conduct needs assessments on local populations
- Tailor training materials for use to support collection of data

- Tailor recruitment materials for use with local populations
- Use best practices for collaboration to provide guidance for the development of partnerships in local settings

Intervention Outcome Modules

- Use behavioral risk findings to guide program planning and intervention delivery
- Use intervention findings and materials for design and delivery of interventions
- Adapt tested interventions for implementation in local settings, maintaining fidelity to core elements and tailoring key characteristics for local context and populations
- Use and/or tailor research protocols and instruments to support targeted data collection on local populations and intervention effectiveness
- Use and/or tailor training materials to support training on delivery of interventions and implementation of program evaluation
- Identify links between tested interventions and existing interventions to provide evidence-based support for existing interventions

Translation Modules

Two multisite projects were funded in 2002 to study the process of translating evidence-based interventions for use by community service organizations. Information on the use of these projects' findings will be forthcoming when the projects are completed.

Behavioral Risk Research Modules can be used by providers for:

- Evidence-based planning
- Needs assessments
- Best practices for collaboration

Intervention Outcome Research Modules can be used by providers for:

- Evidence-based planning
- Intervention design and delivery
- Prevention evaluation on tested intervention models



Youth Drug Injectors, Needle Exchange Use, and HIV Risk in San Francisco and Santa Cruz

Principal Investigators:

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Darryl S. Inaba, Haight Ashbury Free Clinics, Inc., San Francisco
Heather Edney, Santa Cruz County Needle Exchange Program

Module in a Nutshell

Reports on:

- Risk behavior
- Risk assessment
- Participatory research
- Hard-to-reach populations
- Sampling techniques

Provides:

- Best practices for collaboration
- Counseling and testing protocol
- Recruitment and screening tools
- Research protocols

Interventions not tested for effectiveness

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PURPOSE OF MODULE 3

Module 3 presents findings and supporting materials from two interrelated HIV-prevention projects in two California counties. Each project involved collaboration between community-based service agencies and an academic research institution and focused on HIV risk behavior and needle exchange among young injection drug users (YIDU) in San Francisco and Santa Cruz.

The first study, which examined HIV and hepatitis infection among street youth, was conducted collaboratively by Andrew Moss, San Francisco General Hospital and UCSF, and Darryl Inaba, Haight Ashbury Free Clinics, Inc., San Francisco.¹ The subsequent study was carried out at stationary needle exchange sites in Santa Cruz (run by the Santa Cruz County Needle Exchange Program) and in the Mission District neighborhood of San Francisco. This was a collaboration between Andrew Moss, Darryl Inaba, and Heather Edney, Santa Cruz County Needle Exchange, Santa Cruz.² Liaison with and support from the San Francisco Department of Public Health and Santa Cruz County Department of Health played a crucial role in the success of both projects.

This module describes the findings from these two projects, including the prevalence of HIV and hepatitis infections among young injection drug users, the effects of primary and secondary needle exchange, injection drug user HIV risk behavior, incidence of overdose among street youth, and prevention efforts at the various sites. **The projects did not evaluate the effectiveness of testing and counseling or needle exchange programs** at the AIDS service organizations (ASOs).

1. UARP grant PC 97-SF-2016, “HIV Infection and Needle Exchange Use in Young Injectors.”

2. UARP grant PC 97-SF-2016S, “HIV Infection and Needle Exchange Use in Young Injectors.”

The community collaborative approach necessitates the involvement of the community and participation of those being studied. This module describes the collaboration by community providers and researchers. Information is also presented about the interrelationship of needle exchange, risk behavior, HIV and hepatitis infection, and overdose. Research methods are described—including recruitment strategies for hard-to-reach populations, training materials for outreach workers, protocols for blood testing and vaccination programs—as well as how findings might be used for planning and policy change. The findings and policy implications from the two collaborative projects, the description of the iterative process encouraged by the participatory research approach and outreach model, and the procedures and materials utilized during the research offer valuable insights that will be useful for ASOs working in prevention with young IDU populations. Materials used in the research projects are available in the appendices.

RESEARCH PROJECTS

The two projects are presented individually in this section. An overview of each project’s purpose, objectives, and research methods is included, along with descriptions of recruitment, data collection, and training utilized in the study. The first project commenced in San Francisco in 1997.³ Preliminary data generated new questions and initiated extensions to the research project. The second project started in Santa Cruz in January 1999.⁴ Both studies focused on

3. UARP PC 97-SF-2016.

4. UARP PC97-SF-2016S.

5. K. Ochoa et al., “The Challenges and Rewards of Collaborative Study: The UFO Study,” in *Community-Science Collaborations: Preventing AIDS*, edited by B. Bowser et al. (Binghamton, N.Y.: Haworth Press, forthcoming).

Procedures and materials utilized during the research offer valuable insights that will be useful for ASOs working in prevention with young IDU populations.

New priorities for research and interventions developed during the research project period.⁵

Young injection drug users' behaviors put them at extremely high risk for HIV, HBV, and HCV infection.

YIDU = young injection drug users

NEPs = needle exchange programs

infection rates among populations of YIDU and examined the various effects of primary and secondary needle exchange.

San Francisco Site

Young injectors are a high-risk population who frequently are not accessible via treatment or prevention services and who thus present great difficulties for HIV testing and intervention programs. Younger age is also significantly associated with the more risky behaviors of IDUs in general, including borrowing and sharing needles. Needle exchange programs (NEPs)⁶ have figured prominently in HIV prevention. Street youth remain out of reach of the system: poverty, mobility, homelessness, and the illegal status of their drug use are often compounded by animosity from local neighborhood associations.⁷

The YIDU problem is a growing one, for example:

- “In San Francisco, there are an estimated 13,500–15,000 injection drug users and roughly 3000 are <30 years old.”⁸
- AIDS cases among IDUs have more than doubled since 1990, when 5% of the reported cases were among IDUs, to 13.7% in 1996. A comparable rate of increase has not been seen in any other risk group.

6. Originally developed as a hepatitis B prevention strategy, NEPs aim to reduce transmission of HIV and other blood-borne pathogens associated with the reuse of blood-contaminated syringes by providing sterile syringes in exchange for used, potentially contaminated syringes.

7. M. Janofsky, “Wayward Youth Try Patience of Haight-Ashbury,” *New York Times*, August 9, 1998.

8. R. S. Garfein et al., “Viral Infections in Short-term Injection Drug Users: The Prevalence of Hepatitis C, Hepatitis B, Human Immunodeficiency and Human T-0 Lymphotropic Viruses,” *American Journal of Public Health* 86, no. 5 (1996): 655–61.

- Young IDUs, although they are more likely to have relatively short histories of being injectors, have higher incidence rates of HIV, hepatitis B virus (HBV), and hepatitis C (HCV) than older injectors.⁹
- HIV and HBV seroconversion among drug users is associated not only with injection, but also with sexual behavior.¹⁰

Young injectors in San Francisco are demographically distinct from older injectors. They are far more transient, are homeless or marginally housed, and many have not completed the age-appropriate number of school years.¹¹ Unemployment and mental health issues contribute to their marginalized status, making YIDU one of the hardest groups to reach with prevention services, evaluation, and health care.

Community service providers all agree that YIDU are engaging in behaviors that put them at extremely high risk for HIV, HBV, and HCV. In San Francisco, young injectors frequent San Francisco AIDS Foundation HIV Prevention Point primary needle exchange (HPP NEP) sites at lower rates than older injectors, and they commonly use secondary needle exchange.

Secondary exchange represents a network of largely underground needle exchange activity in which designated

9. HBV and HCV are also highly prevalent in IDUs. Since the incidence and prevalence of HBV and HCV is higher than that of HIV, these forms of hepatitis can serve as useful seromarkers for evaluating HIV risk behaviors.

10. UARP PC 97-SF-2016.

11. See the following for more details on YIDU: K. Clements et al., “A Risk Profile of Street Youth in Northern California: Implications for Gender-Specific Human Immunodeficiency Virus Prevention,” *Journal of Adolescent Health* 20 (1997): 343–53; A. H. Kral et al., “Prevalence of Sexual Risk Behavior and Substance Use Among Run-away and Homeless Adolescents in San Francisco, Denver, and New York City,” *Journal of STD and AIDS* 8 (1997): 109–17.

individuals exchange large numbers of used syringes (for several injectors) at official, primary needle exchange sites, and then supply these same injectors with clean syringes. This type of needle exchange activity occurs in locations such as hotels, parks, and on street corners.¹² Concern arose that YIDU infection rates might be high, and the collaboration team determined the need for a study about this high-risk population.

Summary and Purpose

This project grew out of exploratory research among YIDU in San Francisco by a CBO and an academic institution. The collaboration team was composed of the Haight Ashbury Youth Outreach Team (HAYOT) of the Haight Ashbury Free Clinics, Inc. (HAFCI) and UCSF scientists. HAYOT had actual street-based expertise in reaching young injectors.

The major objectives of the study were to:

- Determine the prevalence of HIV, HBV, and HCV infection among injection drug users 29 years and younger (less than 30 years of age) recruited at non-needle exchange sites
- Examine the effects of primary and secondary needle exchange use
- Examine HIV risk behavior
- Examine the effect of contact with outreach services

The effectiveness of counseling and testing was not evaluated in the research project.

Since many of these young people fear and mistrust authority and establishment figures, street-based recruitment is sometimes the only way to contact them. The Collaboration section of this module includes an account of the outreach model utilized by HAYOT, a description of the participatory research

approach used (which prioritizes the expertise of study participants), and the perspectives of the service providers and researchers about working together on the UFO project.

Research Methods

This section presents information about the research protocol and the management of the project. Methods and resources used during the various phases of the project—including recruitment, participation, testing, training, and data collection techniques—are described. Project materials, in many cases developed and tested specifically for this study population, are described here and reproduced in the appendices.

Research Focus and Protocol

To achieve the project goals, a two-year cross-sectional study of HIV, HBV, and HCV infection in young injectors was implemented by the collaborative team. In response to initial findings, pilot vaccine studies and studies about overdosing were implemented. Measurement tools included:

- Screening questionnaire and interview
- Cross-sectional in-depth survey instrument
- Risk assessment
- Serological samples for HIV, HBV, and HCV antibodies

Overall, the study recruited and interviewed 696 injection drug users under the age of 30 during 1997–99. A majority agreed to blood draws; however, many in this sample did not return for results. This meant that the sample sizes for different portions of the research vary. Consequently, only specific segments of the YIDU street-based population in San Francisco are represented and reported on in this module.

12. Annual Progress Report, UARP grant PC97-SF-2016.

13. Ochoa et al., “The UFO Study.”

Study participants developed a project name

A young woman thinking about her test results, suggested “U-Find-Out.” We all laughed at the thought of calling the project “UFO.”¹³



Participatory research prioritizes the expertise of study participants.

Who Was Eligible

- 29 years of age and younger
- Reported injecting drugs in the past month
- Spoke English as primary language
- Agreed to counseling and testing

Confidentiality and **anonymity** were cornerstones to data collection and the research process.

“No research staff from the study were involved in direct recruitment.”

Eligibility

Young injection drug users (YIDU), 29 years old and younger who were on the streets were accessed at non-needle exchange sites in and around the Haight Ashbury, Polk, Mission, and Tenderloin/South of Market neighborhoods of San Francisco.¹⁴

To be eligible, potential participants had to speak English as their primary language, self-report injecting drugs in the past month, and agree to counseling and testing.

Training

The staff at Haight Ashbury Youth Center and Haight Ashbury Free Clinics hired and trained three outreach workers for the project. They participated in the ASO standard outreach training and learned how to teach street-based harm reduction concerning HIV, STDs, hepatitis, injection drug use, and violence. They were also trained to make referrals to service agencies or health clinics when these services were indicated. One critical part of an outreach worker's training involved learning the concept of *confidentiality*, as the clients frequently disclosed sensitive and personal information.

Peer-access interviewers received the same training as the HIV-testing counselors. These were young persons who were familiar with drug use and the street scene. During the project they administered the consent form, pre-test, and interview instruments.

Data Collection

This section describes the process of recruiting eligible YIDU into the study, the screening and enrollment process that took place at the community field sites, and the procedures for collecting data—interviews and blood specimens.

Initial Contact Method—Recruitment

All direct contact with potential participants was made by trained HAYOT youth workers.

Outreach workers visited 20 different sites where young injectors were known to gather, including casual living sites near the four designated neighborhoods in San Francisco. The exact name, location, and activities occurring at any of these sites were confidential, known only to HAYOT peer-access interviewers, and research staff. No research staff from the study were involved in direct recruitment. HAYOT workers visited sites at least twice before attempting any recruitment for the study. All self-reported drug injectors at the recruitment sites were invited to participate in the study. The outreach worker did not assess potential participants for all the inclusion and exclusion criteria but instead referred them to one of the community testing sites.

Screening Procedure

At the community testing sites, a screening protocol (Appendix A), developed specifically for the study, was used. This step-by-step guide included an initial eligibility check of the potential participant. Two resources were used to establish eligibility: the one-page, self-administered screening questionnaire (Appendix B) and the Screener Injection Interview (Appendix C), a brief in-person interview consisting of a series of questions about injection technique designed to identify persons unfamiliar with injection. If there was any question about a person's mental competency to participate in the study, research staff notified one of the study physicians prior to the consent process. Once all requirements were met and it was established that the potential participant was not intoxicated or under the influence of drugs, enrollment in the study commenced.

14. Minors (under 18 years of age), represent a special population, but were included in the sample. See the Ethical Issues section.

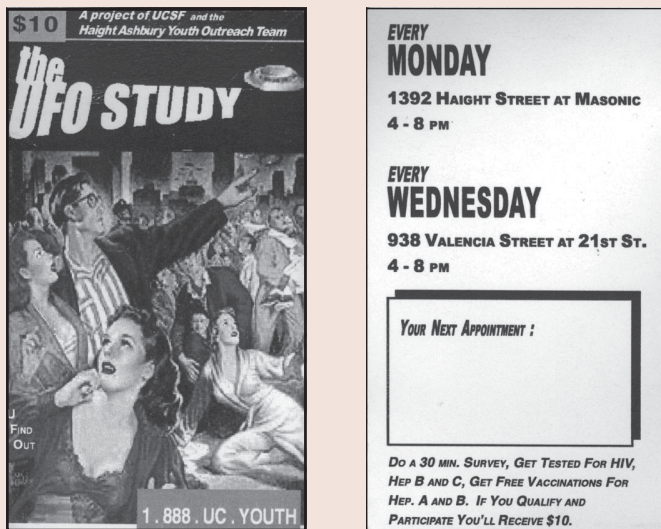


Figure 1
The UFO Study card was used by outreach workers and by staff at the community testing sites.

Enrollment

Once eligibility had been established, the consent and documentation process commenced. Participants were given a screening packet, which included an information sheet (Appendix D), a screening consent form (Appendix E), and the Participant Bill of Rights (Appendix F). A trained interviewer described the study, its purpose, and the procedures involved: the interview, blood draw, and incentives for each visit; the risks of HIV, HBV, and HCV; the reason for the consent form; and issues of confidentiality.

Interviewing

A structured questionnaire (Appendix G) was administered to enrolled participants. This interview took approximately 30 to 40 minutes and included the following topics:

- Injecting drug use behaviors included needle source for first injecting, person who showed injector how to inject (injecting initiator), and history of lending and borrowing used needles and ancillary injecting equipment. In addition, data on injecting behaviors over the past 30 days were collected through questions about frequency of injecting; drugs injected; injecting circum-

stances; reuse of own needles; lending and borrowing of used syringes; sharing cookers, cottons, and rinse water; bleaching syringes; and the duration of injecting by persons from whom syringes were borrowed.

- Sources of new needles over the past 30 days were elicited, including HPP NEP sites (“regular exchanges”), underground and alternative sites (“alternative sites”), exchange with outreach workers and others (“secondary exchange”), pharmacies, purchases on the street, and needles received from friends (“kick-downs”).
- Sexual behaviors in the past six months were elicited and included condom use, number of steady partners, casual partners, and partners with whom the participant had traded sex in exchange for money, drugs, or a place to stay.
- Histories of STD and overdose experience were recorded.

Participants were free to not answer any question, especially those about personal or illegal activities.

Recruitment

- Outreach workers contacted potential participants
- Outreach workers did not assess eligibility
- Outreach workers made referrals to community testing sites where screening and enrollment took place

Incentives

- \$10 for each visit
- Free immunizations against hepatitis A and HBV
- Referrals for health services
- Referrals for food services

Testing

A pre-test counseling session for HIV, HCV, and HBC was administered after the interview by the peer-access interviewer.

The interviewer escorted the participant to the lab area for the HIV, HBV, and HCV blood draw¹⁵ (The phlebotomy process is described in Appendix A, part E). A risk-assessment form (Appendix H) was then completed by the interviewer and placed in the files.

A follow-up session was scheduled in one week for the participant. The following information was provided at that time:

- Test results
- Post-test counseling and referrals
- Information on secondary prevention and harm reduction

A few months into the study, free immunizations against hepatitis A and HBV were made available to all eligible participants.¹⁶

Participants were paid \$10 at enrollment and \$10 when they returned for laboratory results one week later. A hepatitis B protocol (Appendix I) and a hepatitis counseling and testing protocol (Appendix J) were developed for the

15. Presence of antibody to HIV was detected by enzyme-linked immunosorbent assay (Organon Technika, Durham, N.C.) with Western blot confirmation. HBV surface antigen was detected by microparticle enzyme immunoassay. Anti-HCV was detected using a second-generation enzyme immunoassay (EIA-2, Ortho Diagnostics Systems) antibody testing. See J. A. Hahn et al., "Hepatitis C Virus Infection and Needle Exchange Use Among Young Injection Drug Users in San Francisco," *Hepatology* 34, no. 1 (2001): 180–87.

16. The collaboration team decided that the opportunity to reduce future infections through administering of the vaccinations was ethically necessary, even though it is an intervention that could influence the research results. In addition, since a standard HBV vaccination series mandates three visits, a protocol was developed for follow-up of study participants.

YIDU population. These protocols parallel the well-established testing and counseling approach for HIV.

Santa Cruz Site

High-risk young injectors present great difficulties for HIV testing and intervention programs, since they are not normally accessible via treatment or prevention services. However, YIDU do use needle exchanges, although at lower rates than older IDUs. Fixed-site needle exchange programs are one of the few venues where this population can be reached. During the first project in San Francisco, nearly half of the young injectors who participated in the study—and were recruited at non-needle exchange sites—indicated that they had used fixed sites in the San Francisco needle exchange program (HPP NEP sites).

The second research project, an extension of the first project, proposed to transfer the HIV, HBV, and HCV testing model used at the San Francisco community testing sites to a fixed site at the Santa Cruz County Needle Exchange Program (SCCNEP) as well as a second stationary site in San Francisco. This second project targeted the hard-to-reach and hidden IDU in order to extend the study to a different population of YIDUs.

The second study examined HIV and hepatitis infection among two populations: a street outreach population who predominately used secondary exchange and users of a stationary primary needle exchange.

The team proposed to develop a process by which needle exchange sites could explore screening, testing, and counseling as a basis for intervention activities. However, the collaborative team was not sure whether needle exchange users would want to take the additional hour to receive pre-test counseling, complete an interview, and have blood drawn at the stationary NEP site. In addition, it was thought that "hidden" populations

of drug users could be at high risk for HIV but be underrepresented by the street outreach approach used in the original San Francisco study. The San Francisco sample was overwhelmingly white and homeless. This may reflect the “street” population, but there are populations of homed and recent injectors who were not being recruited by outreach-based street recruitment.

The change of focus from street-based recruitment to hard-to-reach homed and new injectors and minorities demanded a different strategy. *Respondent-driven sampling* (RDS), which may increase the ethnic and geographic representative of recruits, was employed in the supplemental study.¹⁷ (The RDS technique employed in the study is described in the Research Methods section that follows.)

Summary and Purpose

This project was a collaborative research project between the Santa Cruz CBO; the Santa Cruz County Public Health Department; the UCSF/SFGH research team; Haight Ashbury Free Clinics, Inc. (HAFCI); At the Crossroads, a Mission District–based outreach organization; and the San Francisco Department of Public Health.

The major objectives of the study were to:

- Determine the prevalence of HIV, HBV, and HCV infection among young (29 and younger) SCCNEP population
- Use respondent-driven sampling to extend the study to hidden or difficult-to-find population groups, including home injectors and new injectors
- Examine HIV risk behavior in this population

- Develop screening, testing, counseling, and intervention processes within a fixed site needle exchange
- Add a stationary site in San Francisco’s Mission District in order to extend the study to Latino and sex-worker YIDU populations in neighborhoods near the original study

The HAYOT team and the UCSF researchers provided supervision and training of SCCNEP staff at the Santa Cruz site.

Research Methods

This section describes the protocol and management of the supplemental project. Sampling and recruitment procedures differed from the initial project, and these are described in detail. Screening, enrollment, interviewing, and testing followed the model from the original San Francisco research project.

Research Focus and Protocol

To achieve the project goals, respondent-driven sampling (RDS) was implemented as a method to extend the study to YIDUs that were not being recruited by the outreach-based street recruitment. Measurement tools included:

- Screening questionnaire and interview
- Cross-sectional in-depth survey instrument
- Risk assessment
- Serological samples for HIV, HBV, and HCV antibodies
- Medical history form

Overall, a total of 108 participants were recruited using the RDS method, and 145 were recruited through the standard street-based outreach method.

17. D. D. Heckathorn. “Respondent-Driven Sampling: A New Approach in the Study of Hidden Populations,” *Social Problems* 44 (1997): 174–99.

18. R. S. Broadhead et al., “Harnessing Peer Networks as an Instrument for AIDS Prevention: Results from a Peer-Driven Intervention,” *Public Health Reports* 113 supp. 1 (1998): 42–57.

The Santa Cruz project targeted hard-to-reach and hidden IDUs who were homed and recent injectors.

The use of peer pressure and involvement of respondents has often harnessed peer networks that proved very useful in recruiting hard-to-reach youth.¹⁸

The project built a “tradition of self-determination, positive action, and empowerment in one of the least accessible of all HIV risk populations.”²⁰

San Francisco outreach workers trained the Santa Cruz team.

RDS permitted study respondents to play an active role in the outreach process.

Sampling

RDS permitted respondents to play an active role in the outreach process. Respondent-driven sampling is a technique that uses the intrinsic networks of the respondent population and rewards the first (“seed”) group of respondents to bring in additional potential study subjects on their own. The networks can in fact be driven in specific directions by using specific seed populations to begin the sampling. In this study, hard-to-reach YIDU were targeted.¹⁹

Eligibility

Eligibility inclusion criteria remained the same except for the change in population:

- 29 years of age and younger
- Reported injecting drugs in the prior month
- Agreed to counseling and testing
- Hard-to-reach populations defined as either homed or new injector, Latino, or female sex worker

Training

SCCNEP volunteers participated in hands-on training at study sites in San Francisco (Appendix K). They developed skills to provide youth-specific HIV and hepatitis testing and counseling. HAYOT staff supervised and trained SCCNEP staff, and volunteer health providers from SCCNEP worked with medical staff from the San Francisco team to learn the project phlebotomy and vaccination techniques. A medical encounter form was developed and used with the Santa Cruz population (Appendix L).

19. RDS is a chain-referral sampling that was designed to reduce several sources of bias associated with choice of initial participants, volunteerism, and masking. See D. D. Heckathorn et al., “Extensions of Respondent-Driven Sampling: A New Approach to the Study of Injection Drug Users,” *AIDS and Behavior* 6, no. 1 (2002): 55–67.

20. Ochoa et al., “The UFO Study.”

dix L). HAYOT staff also trained the Mission District Outreach staff and supervised data collection. An exit survey was also added to the instruments used among the San Francisco population (Appendix M).

Data Collection

Recruitment

Outreach staff recruited seed participants following the procedures described in the Research Methods section for the initial San Francisco project. These participants, after screening and completion of enrollment, were offered financial incentives to recruit their peers into the same process. The seed participants were given several recruitment coupons and instructed to pass them on to their peers and to direct them to a stationary needle exchange for screening. The seed participant (recruiter) was paid \$10 for each recruited peer. After screening and enrollment, all new recruits were offered the same dual incentive as the seeds; that is, everyone was rewarded for both completing enrollment and recruiting peers into the study.

Interviewing and Testing

The process used in the original San Francisco study was followed at the stationary needle exchange venues. All enrolled participants were advised that they could withdraw from the study at any time.

ETHICAL ISSUES

The collaboration teams in both the initial and supplemental studies responded to various ethical concerns that arose during the research.

Minors

YIDU under 18 years of age were included in both studies. Minors represent a special population, and all effort was taken, using the expertise and guidance of HAYOT staff, to contact the subjects in a non-intrusive, non-aggressive man-

ner. The collaborative research team believed that interviewing minors was critical; young injectors are the group most likely to not yet be infected with HBV, HCV, and HIV, yet are most at risk for contracting these infections. Based on descriptions of youth at needle exchange and other high-risk sites, most youth in the study were defined as “emancipated.” Most young injectors do not reside with their parents and are financially independent.

Testing and Counseling

Testing and counseling was anonymous. For those electing to receive vaccinations, a written consent was obtained for confidential participation. This confidentiality allowed outreach staff to collect contact information for vaccination reminders. The consent process entailed a discussion with potential participants about the study’s objectives, procedures, risks and benefits, reimbursement, costs, and alternatives. After the procedures stated in the consent form were discussed with participants and any questions posed by the participants answered, they signed the consent form (see Appendix E) if they wished to participate. Participants were provided copies of both the consent form and the Participant Bill of Rights (see Appendix F).

Potential Risks

Potential risks to participants included the following:

- The disclosure of sensitive information during the interview: referrals for support and counseling were offered to all participants.
- Potential loss of confidentiality: names were collected only on the consent forms and contact tracing forms; all interview instruments had unique identifiers and were kept in a locked file.

- Submitting to venipuncture for blood specimen collection and to intramuscular vaccination.

RESEARCH FINDINGS

This section describes results of the research among the YIDU in San Francisco and Santa Cruz. The data were obtained through questionnaires, interviews, risk assessments, and serological specimens. The findings include data on needle exchange behavior; IDU risk behavior; HIV risk behavior; and HIV, HBV, and HCV prevalence. (Sample sizes vary for different domains.)

In a combined sample of 213 San Francisco and Santa Cruz participants, the average age was 22, with a median of five years of injecting and a median of three years of needle exchange use. Bisexuality was common. Seropositivity rates were 6% for HIV, 42% for HCV, and 33% for HBV. A total of 46% reported borrowing a used syringe within the past year, even though 84% of the participants had used some form of needle exchange, most frequently through a secondary exchange network. These findings, originally reported in the *California Collaborations* newsletter, Summer 2000, are presented in the table on page 12.

In addition to the aggregate analysis presented on page 12, the investigators ran multiple analyses of data from the San Francisco and Santa Cruz sites on various data sets. Results from these analyses follow, on pages 13–15. Sample sizes are identified in parentheses.

By testing people, you’re making that the priority—when food, drugs, money, and shelter are always what come first, before health.²¹

—ASO provider

Minors

- Most likely to not yet be infected with HBV, HCV and HIV
- Most at risk for contracting these infections

21. Ochoa et al., “The UFO Study.”

KEY RESULTS (San Francisco and Santa Cruz sample combined, n=213^a)

Demographics

Age

- 24% 15–19 years
- 46% 20–24 years
- 30% 25–29 years

Gender

- 65% male
- 34% female
- 1% transgender

Race

- 78% white
- 22% non-white

IDU Behavior

Duration of Injection Drug Use

- 28% less than 3 years
- 22% 3–5 years
- 22% 5–7 years
- 29% 8 years or more

Days Injected per Month

- 19% 1–4 days
- 17% 5–10 days
- 23% 11–20 days
- 40% 21–30 days

Last-Used Syringe Borrowed

- 27% in past month
- 19% between 1 month and 1 year
- 17% more than 1 year
- 37% never

Needle Sources Used in Past 30 Days

- 8% primary NEP sites only^b
- 43% secondary exchange only^c
- 33% primary and secondary both
- 16% no exchange
- 65% exchange for others

Sexual Identification and Behavior

Sexual Orientation

- 56% heterosexual
- 41% bisexual
- 4% homosexual

Sexual Risk in Past 6 Months

- 62% steady partner
- 54% any casual partner
- 16% sex for drugs or money

HIV, HBV, and HCV Prevalence^d

(Samples were obtained from 203/213 subjects who agreed to testing)

6% HIV+

- 67% of HIV+ coinfecting with HBV+
- 77% of HIV+ coinfecting with HCV+

33% HBV+^d

- 71% of HBV+ coinfecting with HCV

42% HCV+

- 54% of HCV+ coinfecting with HBV

^aData were collected from 213 subjects surveyed in San Francisco and Santa Cruz from 1997 to 1999.

^bPrimary = stationary NEP sites.

^cSecondary = underground sites and informal exchange networks.

^dParticipants with serological evidence of vaccination were excluded from HBV+ statistics; therefore, the total number that tested HBV+ (Anti-HBc or HbsAg positive) was 181.

San Francisco Site

Prevalence²²

HIV (n=312)

Demographics:

- 68% male
- 31% female

Prevalence:

- 6% HIV+ (88% in males)
- 93% of those HIV+ coinfecting with HBV and HCV

HBV (n=312)

Demographics:

- 68% males
- 31% females

Prevalence:

- 29% HBV+ (core antibody or surface antigen)

HCV (n=312)

Demographics:

- 68% males
- 31% females

Prevalence:

- 45% HCV+

IDU Risk Behaviors

Factors Associated with HCV (n=312)²³

- Age
- Number of years injecting
- Injection by sex partner at initiation
- Ever injected with someone else's used needle
- Used methamphetamine or heroin in the past year
- Injected daily
- HBV infection
- Bleached last time injected with a borrowed needle (protective)
- Snorted or smoked cocaine (protective)

22. K. Ochoa et al., "Overdosing among Young Injection Drug Users," oral presentation, Preventing Heroin Overdose, Seattle, Wash., January 2000.

23. Hahn, et al. "Hepatitis C Infection."

Gender Specific (n=310)²⁴

Female IDUs:

- Significantly younger than their male counterparts.
- Reported having injected for 3–5 years
- Over half injected self
- 1 of 3 were likely to shoot alone

Male IDUs:

- Most reported injecting for more than 8 years
- 78% males injected self
- Over half shoot alone

Overdose History (n=312)²⁵

Demographics:

- Median age 22
- Median years injecting 5

Overdose experience:

- 55% overdosed at some time
- 72% overdosed more than once
- Median number of overdoses was 3
- 67% of those who overdosed had a friend help them recover
- 35% got medical attention via 911 or a ride to the hospital

Witnessed overdose:²⁶

- 75% witnessed an overdose, and at most recent occasion the following occurred:
- 52% called 911
- 61% performed CPR
- 72% kept the person awake by walking them around or shaking them
- 11% reported that the person died

24. L. Vadnai et al., Abstract, 17th Annual UARP Meeting, San Francisco, 2000.

25. Ochoa et al., "Overdosing among YIDU," 2000.

26. See P. J. Davidson et al., "Witnessing Heroin-Related Overdoses: The Experiences of Young Injectors in San Francisco," *Addiction* 97, no. 12 (2002): 1511–16.

Significant Findings

- The majority of HIV infection is in males.
- HIV+ are most often also infected with HBV and HCV.
- Prevalence of viral infections is high among YIDU in San Francisco, especially HCV.
- Seroprevalence increased with duration of injecting for all three viruses.
- No injection-related variables were associated with HIV infection, but 93% were coinfecting with HCV or HBV.

Young female injection drug users are younger [and] have less injection experience than their male counterparts.³⁵

Significant Findings

YIDU who borrow needles and those who are gay or bisexual are at the highest risk both for overdosing and for HIV infection: 78% of reported overdoses were in subjects with one or both of these risk factors.³⁶

Overdose Risk Behaviors

Certain behaviors predict those most likely to have ever overdosed:

- Ever been tested for HIV
- Exchanged used syringes in last 30 days
- Identify as MSM
- Recent heroin use
- Recent speedball (heroin and cocaine mixed) use
- Used someone else's syringe in the 30 days prior to interview

Sexual Behaviors

General (n=410)²⁷

- 3% HIV+
- Males were at a much higher risk of being infected with HIV virus

Independent predictors of HIV infection among the males were:

- MSM identity²⁸
- Residing in San Francisco more than 1 year

Gender Specific (n=310)²⁹

Females:

- 81% reported sex with IDU partner
- 73% reported condom use
- 29% reported STD

Males:

- 63% reported sex with IDU partner
- 69% reported condom use
- 23% reported STD

Needle Exchange History

General (n=410)³⁰

In the month prior to their enrollment in the project:

- 79% exchanged syringes
- 46% exchanged only via alternative or secondary exchanges

- 50% obtained at least as many new syringes as injections
- 47% had lent their used syringe
- 86% reported that it was very easy or somewhat easy to obtain a new syringe when one was needed
- 28% reported using someone else's used syringe, despite "easy" access to new syringes³¹

Gender Specific (n=310)³²

- 71% of females reported exchanging needles for someone else
- 54% of males reported exchanging needles for someone else

Prevention Access History (n=410)³³

- 85% ever had contact with an outreach worker
- Majority had contact in prior month
- Contact with an outreach worker (ever) *not* associated with HIV seropositivity
- Contact with an outreach worker (ever) *not* associated with decreased needle borrowing
- Outreach worker contact related to higher use of secondary needle exchange

Hepatitis Vaccination History (n=209)³⁴

- 123 HBV negative (no HBV markers)
- 71% returned for results
- Majority (71/87) accepted the first of three vaccine doses for HBV

27. Annual Report, PC97-SF-2016.

28. See K. P. Shafer et al., "Prevalence and Correlates of HIV Infection among Young Injection Drug Users in San Francisco," *Journal of Acquired Immune Deficiency Syndromes* 31, no. 4 (2002): 422–31.

29. Vadnai et al., Abstract.

30. Annual Report, PC97-SF-2016.

31. J. A. Hahn et al., "Hepatitis C Virus Seropositivity among Young Injection Drug Users: Relationships and Risks," *Journal of Infectious Diseases* 186, no. 11 (2002): 1558–64.

32. Vadnai et al., Abstract.

33. Annual Report, PC97-SF-2016.

34. P. G. Lum et al., "Low Rates of Hepatitis B Vaccination Among Young Injectors in San Francisco," Abstract attached to Annual Progress Report, UARP grant PS97-SF-2016.

35. Hahn et al., "Hepatitis C Infection."

36. Ochoa et al., "Overdosing among YIDU," 2000.

Santa Cruz Site

IDU and Needle Exchange Behaviors (n=253)³⁷

Respondent Driven Sampling (n=108)

- 0% HIV+
- 71% injected more than once per day
- 23% used alternative and underground exchanges
- 48% used secondary exchange

Community Outreach Participants (n=145)

- 3% HIV+
- 85% injected more than once per day
- 31% used alternative and underground exchanges
- 37% used secondary exchange

Hepatitis Vaccination History (n=108)³⁸

Serology:

- 92% (N=99) consented
- 95% returned for results

HBV and hepatitis A:

- 65% negative (no HBV markers)
- 88% accepted first of three HBV vaccine doses and the single hepatitis A vaccination

Use of Data

During the two project periods, findings were transformed into various actions and activities. Some examples include the following.

Needle exchange programs: The Santa Cruz County Needle Exchange Program produced successful mobilizations for harm reduction and HIV prevention. SCCNEP produced many outstanding small media. The project succeeded in

bringing legitimacy to needle exchange in Santa Cruz and became nationally known for novel interventions, many of which have been replicated and adopted in other cities. SCCNEP was the first needle exchange program in the U.S. to offer hepatitis testing and vaccination to clients, an intervention which is now being widely adopted nationwide.³⁹

Window of opportunity: Given that HBV is preventable and vaccination is well accepted, HBV prevalence is unacceptably high among YIDU in San Francisco. A window of opportunity exists for early HBV vaccination of YIDU.

Interventions: The findings indicate that those at highest risk for viral infections are often gay/bisexual men and individuals who share needles. Interventions aimed at preventing viral infections among YIDU need to address both injection and sexual practices.

Policy for overdose prevention: “Our result has policy implications, since injecting drug users are a major focus of HIV prevention efforts in the U.S. The current study strongly suggests that outreach and intervention attempts directed towards young injectors at risk for HIV should include overdose prevention efforts as well.”⁴⁰

Outreach materials: SCCNEP used overdose data and interviews with participants from the UFO Study in an issue of its *Junkphood* 'zine. This worked well, since the data was collected from the 'zine's target audience. An online version was placed on an SCCNEP web site: <http://www.overdoseprevention.org>.

Raising awareness: Awareness of the overdose problem among drug users and their providers is critical. Developing effective interventions should become a

Findings Transformed into Action

- Offer vaccinations at NEPs
- Interventions need to address **both** injection and sexual practices
- Develop outreach materials for print and web

37. UARP PC97-SF-2016S.

38. Final Report, UARP grant PC97-SF 2016S.

39. UARP PC 97-SF-2016S.

40. Annual Report, PC97-SF-2016.

Overdose Awareness

- In young injectors surveyed in San Francisco, 65% of those who overdosed received no medical help at their last overdose⁴⁵
- YIDUs' fear of arrest creates a barrier to accessing emergency services
- Developing effective HIV interventions that include overdose prevention should become a priority

True collaborative research is a kind of alchemy.⁴⁶

priority. In particular, obstacles to seeking emergency services should be defined and addressed. Since fear of arrest is one potential barrier, fatal overdoses could be prevented through protocol changes in the emergency response system, thereby limiting police involvement during an overdose. Also, a set of standard medical interventions could be implemented.⁴¹

COLLABORATION

This section describes the organizations and people that contributed to the research projects in San Francisco and Santa Cruz, the key components and processes that took place during the collaborative research, and suggestions for best practices in collaborative projects between researchers and community-based organizations. There are many voices from this collaboration, and they speak out in this section.⁴²

The community collaborative approach necessitates the involvement of the community and the participation of those being studied as well as those carrying out the study. There are pros and cons to this type of collaboration (Appendix N), but in general it worked because it dissolved the barriers between the researchers and the subjects of the research. Collaboration provided a vital intermediary between the researchers and the subjects. It was both a probe into lives of young injectors and a buffer to protect the researchers from the psychic wounds of working with them—a valuable buffer in the case of this very high-risk, very self-destructive young population.⁴³

41. Annual Report, PC97-SF-2016.

42–44. Ochoa et al., “The UFO Study.”

45. K. Ochoa et al., “Overdosing Among Young Injection Drug Users in San Francisco,” *Addictive Behaviors* 26 (2001): 453–60.

46. Ochoa et al., “The UFO Study.”

The naming of the project provides an example of collaboration. One night at a community study site in San Francisco, the new team of HAYOT and UCSF staff asked the study participants to come up with a name. A young woman, thinking about her test results, suggested, “U-Find-Out,” and everyone laughed at the thought of calling the project “UFO.” Soon all the outreach materials featured UFO images, and everyone involved began referring to the project as the “UFO Study”⁴⁴ (see Figure 1, on page 7).

Collaborative Partners

This section describes the various agencies and organizations involved and the roles they played in the collaborative projects in San Francisco and Santa Cruz.

Research Institution

The Department of Epidemiology and Biostatistics at University of California, San Francisco, served as the coordinating site for both studies. The academic research team members had offices and facilities at UCSF and San Francisco General Hospital. The academic principal investigator (PI), an epidemiologist, and various team members worked out of these offices.

The UCSF Medical Campus is located near one of the sites of a collaborating partner, the Haight Ashbury Free Clinics, as well as the community field sites utilized during the research project as drop-in centers.

Community-based AIDS Service Organizations

Haight Ashbury Free Clinics, Inc. (HAFCI), San Francisco

The mission of this institution is to provide free, non-judgmental, quality health care to those in need. Services include primary care services, HIV treatment and prevention, and services for the homeless. It primarily serves uninsured and underinsured “working poor.” Outreach services target hard-to-reach and at-risk

persons needing accessible care, including poor, homeless, substance abusing, and mentally ill individuals. Founded in 1967, HAFCI today has 20 paid staff who provide primary care and special services (see <http://www.hafci.org>).

One of the PIs, the CEO of HAFCI, oversaw that institution's participation. The deputy director provided daily administrative supervision to project activities and was the liaison with the UCSF team.

Haight Ashbury Youth Outreach Team (HAYOT)

A separate program at HAFCI for youth outreach, HAYOT was part of the collaboration team. Its members had real street-based expertise in accessing young injectors. HAYOT has a commitment to work with young people that no one else wants to serve. The focus is on hardcore users that other service providers will not accept.

Santa Cruz County Needle Exchange Program (SCCNEP)

SCCNEP is a community-based, user-driven organization serving injection drug users. Its primary goal is to slow the spread of blood-borne diseases and promote a sense of community. Services include drop-in harm reduction/HIV resource center, hepatitis clinic, overdose prevention, syringe exchange and distribution of "other" safe injection equipment and safer sex supplies, wound care, holistic health care services, general street outreach, and outreach specifically to women involved in the sex work industry. SCCNEP's clientele includes a large number of young injection drug users at both street-based syringe exchange sites and the drop-in center (see <http://www.needleexchange.com>).

Run primarily by a volunteer base of 25 persons and 3 paid staff, the drop-in center is located in the city of Santa Cruz. The syringe exchange services are

available seven days a week at street-based sites and through home visits and secondary exchange.

One of the PIs is executive director of the HIV Education and Prevention Project of Santa Cruz County. She provided general supervision and oversight for the staff and project activities and, as project coordinator, oversaw testing/vaccinations and staff during the research project. She was also the liaison with HAYOT and UCSF staff.

Dolores Street Community Services (DSCS)

This nonprofit multiservice organization addresses the needs of the people in the Mission and Castro districts, providing housing, sanctuary, and support. A weekly needle exchange is utilized by women only, making it a familiar location for female IDU. Located in the Latino community, DSCS was used as an additional stationary community site during the second project. On a weekly basis, project staff used it as a venue for conducting interviews, specimen collection, HIV/hepatitis notification and counseling, and hepatitis A and B vaccinations.

Public Health Departments

The San Francisco Department of Public Health is located at 25 Van Ness Avenue at Market Street. It has specific programs in HIV health services, an AIDS Surveillance Unit, and the San Francisco HIV Prevention Planning Council (HPPC). The Public Health Department of Santa Cruz County, Health Services Agency, provides the following programs: the Santa Cruz AIDS Project (SCAPS) and a drop-in center in Santa Cruz, as well as HIV testing and education and prevention services.

Voices of the Team⁴⁷

Collaboration dissolved the barriers between the researchers and the subjects of the research.

We probably could not have done this study *except* as a community collaboration. However, there is a price for this, and the price was learning to live with culture clash. —PI

The study is a well-oiled vaccinating, testing, harm-reducing, data-collecting machine staffed by a skeleton crew of volunteers that love the study and what it's about. —Peer interviewer/counselor, former heroin addict, and client of HAYOT

All collaborations need a marriage counselor, someone who can't really take sides, whose job it is to help everyone communicate.

—Field director of project

47. Ochoa et al., "The UFO Study."

Success of research is measured by what happens during the process of the study as well as by study findings.⁵⁵

The UFO study allowed users to step into the light and feel the validation of someone official paying attention to their health needs and offering real assistance.⁵⁶

Processes and Key Components of Collaboration

Shared History and Common Goal

The collaboration grew out of exploratory research and long-term interest in studies of HIV in IDU by members of the team. A relationship developed between UCSF and HAYOT during a small, street-based, HIV prevalence study.⁴⁸ This relationship became formalized during the first project described in this module.⁴⁹

Together, the service providers and the researchers made the project work. CBO staff, who understand the needs and concerns of the population being served, worked with the researchers to identify important study questions—questions that define and illuminate the specific problems of the population. Using this approach, the success of research is measured by what happens during the process of the study as well as by the publication of study findings. “One of the most important things that happened in the UFO study was the development of new priorities for research and intervention during the time in which we carried out the research.”⁵⁰

The collaborative approach is an exercise in participation for both those being studied and those doing the studying. Collaborative research recognizes the existence of expertise among study participants as well as the organizations that serve them, and therefore seeks their participation. With this approach, which values the opinions of the research subjects, a more equal distribution of power exists between the professional researcher and the community organization than in the traditional research process.⁵¹

48. Funded by the Kaiser Family Foundation in 1996.

49. UARP PC97-SF-2016.

50–51. Ochoa et al., “The UFO Study.”

Collaborative Model

Providers, researchers, peer outreach workers, and interviewers worked together at the community sites. An approach evolved that combined theoretical principles of harm reduction with the experiences of team members. These principles included the involvement of active and past drug users in the creation of programs and polices designed to serve them.⁵²

Participation by the study population in a project as outreach workers is a natural extension of harm reduction. Importantly, in research of young injectors elsewhere, “privileged access interviewers” gained access at a level not available to orthodox research staff.⁵³

Iterative Process

During the project, the various team members shared ideas across the boundaries of expert categories.

Research Focus

According to the PIs, the team wanted not only to design compelling research that would further the health status of young injectors in the future but also to create a research environment where a young person’s health status could immediately be influenced.

As new information was observed and shared, additional research questions were developed. “These reorientations of our focus during the course of the study were the direct result of the close involvement of the researchers with the service providers and the young injectors themselves.”⁵⁴ These reorientations included the following realizations:

52. See Harm Reduction Coalition, *Working Together Towards Individual and Community Health* (New York: Harm Reduction Coalition, 1997).

53. P. Griffiths et al., “Reaching Hidden Populations of Drug Users by Privileged Access Interviewers: Methodological and Practical Issues,” *Addiction* 88 (1993): 1617–26.

54–56. Ochoa et al., “The UFO Study.”

- HBV and HCV were as important as HIV in this population.
- Needle exchanges were a potential venue for the kind of interventions being studied.
- Vaccination was important in the young injector population (see Ethical Considerations, below).
- Overdoses were the major cause of death in the subjects (young injector population), so overdose and overdose prevention also needed to be investigated.

Ethical Considerations

Disclosure of negative serological status for HBV to a high-risk population without offering the available immunization posed a major ethical dilemma. The team immediately realized it needed to respond to the community's needs. Donations of the needed vaccines were solicited from the San Francisco Department of Public Health. The community sites, where up to 25 young people were seen in one evening, became drop-in centers where vaccination programs took place. The vaccine intervention evolved into a follow-up study called UFO 2.

Alternative Perspectives from Team Members

Numerous collaborators contributed to the success of this project. Members of HAYOT, service providers, and research staff often had divergent priorities. In particular, the line between service provision and research was a major point of contention. Conflicts arose at weekly staff meetings; debates about prioritizing the questionnaire over the counseling created tension between providers and researchers. Yet disagreements were heard and considered, and everything was brought to the table and ultimately resolved.

Resource Commitment

Funding issues loomed large in everyone's mind during this community collaborative project. CBOs operate in an insecure financial environment, as do many researchers, who are dependent on grants from state and federal agencies. During this research, the new projects that evolved out of the iterative process and the team's response to community needs (e.g., vaccination programs) meant that funding storms plagued the project.

Continued funding for staff salaries was a problem. Volunteer work supported much of the work at the drop-in centers, especially at SCCNEP. Contributions in kind from other agencies helped to support numerous aspects of the project.

The San Francisco Department of Public Health and Santa Cruz County Department of Health donated ample supplies of hepatitis A and hepatitis B vaccines. Clinicians from the Tom Waddell Clinic of the City and County of San Francisco and HAFCI provided the first vaccinations to study participants at the community sites.

Best Practices for Collaboration

The scientists and providers who worked together on the San Francisco and Santa Cruz projects point out that pressure was put on the academics by the community side of the collaboration to come up with intervention strategies, rather than just testing people.⁵⁷ This challenged the collaboration team. Many valuable lessons were learned and will be useful for other research teams and CBOs to consider when conducting community collaborative research:

Benefits of This Collaboration

- Needle exchange was legitimized in the eyes of the Santa Cruz County Health Department.
- New relationships were developed between CBOs and government and funding agencies.
- Technology was transferred from community to research institution.
- Vaccines were made available at NEPs.
- Harm reduction model was followed.

57. Ochoa et al., "The UFO Study."

We have a staff of experts in all respects, both science-wise and street-wise.⁵⁸

Collaborative participatory research can become participatory action—when the act of research creates change.⁵⁹

- Joint training and sharing of knowledge and experience between staff on different site teams is vital.
- Regular meetings of collaboration team must be held.
- Disagreements and conflict all need to be brought to the table.
- The project director must listen to all points of view, have the authority to make final decisions, and assist the team with compromise.
- Resource commitment from local government agencies (health departments, police departments, hospitals) is necessary.
- Research should inform services, not duplicate them.
- Use of a participatory research model is invaluable—recognize expertise among service organizations and the study participants.
- Opinions of the research subjects must be valued.

success of the collaboration was the use of the participatory research model and adherence to the harm reduction model. These models emphasized the crucial role of the research subjects, YIDU, in the research process and the sharing of decision making by the community providers and the researchers.

New relationships were developed between local CBOs and government and funding agencies as a result of this collaborative research. Importantly, needle exchange was legitimized in the eyes of a local county health department as a result of the academic-CBO collaboration.

CONCLUSION

The iterative process that resulted from the participatory research approach and outreach model utilized in this research allowed new research questions to be generated. Interventions such as vaccination programs were initiated in response to the community need. The procedures and materials used during this collaborative research project offer valuable insights for providers working in prevention with young IDU populations.

This research project reflects the growing pains that accompany community collaborative research. However, the team described benefits that outweighed the problems. This collaboration of community providers, academic researchers, and street youth participants is unique in the prevention intervention research community. A key factor in the

58–59. Ochoa et al., “The UFO Study.”