

May, 2006

COMMUNITY BASED HIV/AIDS RESEARCH: GUIDELINES FOR SUCCESSFUL PARTNERSHIPS

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The *Guidelines* will be updated as necessary based on the experience of those utilizing them in their research collaborations. If you would like to provide feedback to CIRA, have questions, or would like to be connected to anyone referenced in the *Guidelines*, please contact CIRA's Community Research Core in writing at 40 Temple Street, Suite 1B, New Haven, Connecticut 06510, via phone at (203) 764-4333, via fax at (203) 764-4353, or via e-mail to Leif.Mitchell@yale.edu.

CIRA would like to sincerely thank all those community research partners and CIRA scientists who participated in the development of this document, including but not limited to:

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EXECUTIVE SUMMARY

Community Based HIV/AIDS Research: Guidelines for Successful Partnerships was created to highlight local models of community based research (CBR). The Center for Interdisciplinary Research on AIDS (CIRA) Community Research (CR) Core developed the *Guidelines* with assistance from community partners and scientists through a series of workshops to reflect on and document local models of CBR that represented some successful community based HIV/AIDS initiatives conducted in Connecticut since the start of the epidemic.

The *Guidelines* summarize the broad themes that emerged during the course of the workshops, including various strengths and weaknesses of the collaborations in order to distinguish common features contributing to the formation, success, and continued maintenance of CBR. The *Guidelines* address the components needed to establish strong, practical, productive collaborations between researchers and communities in order to yield outcomes likely to meet the objectives of all parties while maintaining best practices in public health research. It also identifies potential gaps that should be addressed in future research efforts. We anticipate that research endeavors utilizing CBR techniques can and will benefit from reviewing and integrating principles from the *Guidelines*.

Each case study describes specific strengths and weaknesses associated with conducting CBR based on their particular research collaboration. However, there were recurrent themes across all of the models. The workshop on challenging collaborations and the IDU research participant workshop added further depth to our understanding of the collaborative research process of CBR. The following are our recommended *Guidelines for Successful Partnerships on Community Based HIV/AIDS Research*.

Establish open communication.

Build trust between research collaborators.

Choose scientists and CBOs carefully.

Seek on-going community input in a variety of ways.

Establish a liaison between university/institutional administration and the CBO.

Delineate clear roles for each partner.

Establish a clear project identity.

Ensure each partner has a voice.

Bring the project to the community.

Disseminate findings from the project.

Consider sustainability of the project.

BACKGROUND

Collaboration with the community allows scientists involved in public health to not only discover relevant health issues but to approach them in a way that is effective, sustainable, and reflective of a community's strengths and needs. Public health research with active community involvement can significantly inform methodology by providing a tenor of appropriateness, allowing for shared community and researcher interpretation and presentation of research findings, and resulting in the development of useful interventions and policy advocacy.

The Center for Interdisciplinary Research on AIDS (CIRA) was established in 1997 through a grant from the U.S. National Institute of Mental Health (NIMH) and National Institute on Drug Abuse (NIDA). Our mission is to conduct applied research aimed toward the prevention of HIV infection and the reduction of the negative consequences of HIV disease in vulnerable and underserved populations. CIRA's Community Research (CR) Core facilitates the development and dissemination of community based HIV prevention research and findings. The CR Core provides CIRA-affiliated scientists with a means of identifying community research priorities while working to strengthen the research capacity of its community partners. Through a series of community meetings prior to CIRA's funding as a Center in 2001, scientists and a Community Advisory Board (CAB) identified a need within the HIV/AIDS community – to create local guidelines for successful partnerships in community based HIV/AIDS research (CBR). Although overarching guidelines exist in scientific publications and by other research centers, it was felt that Connecticut's experience was unique and that the creation of locally relevant guidelines would be worthwhile to support local CBR efforts.

In 2002, the CR Core began to develop a process to create the Guidelines. The CR Core sponsored a series of workshops to reflect on and document local models of CBR that represented some of the successful community based HIV/AIDS initiatives conducted in Connecticut since the start of the epidemic. The workshops provided an opportunity to disseminate the results and research process involved in these models to Yale investigators, community members and policy makers across the state.

A total of four workshops were held. Each workshop examined a variety of partnerships and collaborative research projects in which CIRA affiliated scientists were involved. The objectives of the workshops were to hear and document the experiences of researchers and community partners on CBR projects; to provide a space for a dialogue on CBR with community partners and the CR Core; and to develop local guidelines for successful partnerships in community based HIV/AIDS research. The CR Core carefully selected research partnerships with a history of collaboration. Many of the partnerships existed for several years prior to CIRA's inception and resulted in successful interventions and policy changes. The participants for each of the workshops included CR Core members; CIRA-affiliated scientists from Yale; scientists from the Institute for Community Research and the Hispanic Health Council (research organizations in Hartford, CT, which collaborate with CIRA); CIRA Community Advisory Board (CAB) members; and other community collaborators. An outside facilitator or a CR Core member moderated the workshops and guided the participants through a series of questions developed by the CR Core.

The first workshop held on March 7, 2003, included case studies of needle exchange research interventions in New Haven and Hartford; the second workshop on June 2, 2003 discussed two other case studies, one on HIV risks among pregnant teens in New Haven and the other on peer health advocates for injection drug users (IDUs) in Hartford. During the workshops both academic and community partners held open discussions about their experiences in their respective projects and partnerships. The partners identified characteristics of successful working relationships between community and scientific partners that enabled them to accomplish their research objectives. The divergent partnership teams in both cities demonstrated that there is no singular model for success. The projects included in the first two workshops are as follows:

- *The Hartford Community Alliance for AIDS Prevention (CAAP)*
- *New Haven Needle Exchange Program Evaluation Project*
- *Connecticut Women's Health Project*
- *HIV Prevention in High-risk Drug Use Sites: Project RAP (Risk Avoidance Partnership), Institute for Community Research*

The third workshop, “The Experience of IDUs in CBR,” was held on August 24, 2004. The CR Core recognized that much of the epidemic in Connecticut can be attributed to injection drug use (IDU) and that a certain expertise has developed among CIRA-affiliated scientists working with this population. Therefore, the third workshop focused on the experience of IDUs as participants in CBR.

The fourth workshop, “Challenging Collaborations and University Barriers to CBR,” was held on March 31, 2005. The CR Core acknowledged the importance of reviewing lessons learned from collaborations that were challeng-

ing and at times less than successful. Therefore, the fourth workshop focused on the experience of scientists and community partners in collaborations which sometimes failed and were discontinued.

The product of these workshops is Community Based HIV/AIDS Research: Guidelines for Successful Partnerships. The Guidelines summarize the broad themes that emerged during the course of the workshops, including various strengths and weaknesses of the collaborations in order to distinguish common features contributing to the formation, success, and continued maintenance of CBR. The Guidelines address the components needed to establish strong, practical, productive collaborations between researchers and communities in order to yield outcomes likely to meet the objectives of all parties while maintaining best practices in public health research. It also identifies potential gaps that should be addressed in future research efforts. We anticipate that research endeavors utilizing CBR techniques can and will benefit from reviewing and integrating principles from the Guidelines.

Please note: The following terms are used interchangeably in various research and community circles. These terms are used throughout the Guidelines and in order to provide some consistent and clear information for a productive dialogue, we've made an attempt to provide some statements about what we mean when referring to these terms:

“**Community**” refers to a general, broad group of people including community based organizations, scientists, and individuals at large.

“**Community Based Organizations**” or “**CBOs**” refer to non-profit agencies in which research is not the agency's primary mission. The CBOs may or may not be directly involved in the provision of HIV/AIDS prevention and care services.

“**Community partner**” refers to a CBO, a member of a CBO, or a resident of community, who is directly interacting with a scientist on a research project.

“**Scientist**” refers to investigators from universities or other non-profit organizations whose primary mission is research.

“**Research participants**” refers to the individuals who are part of a research study.

“**Research collaboration**” refers to the CBOs, community partners, scientists, universities and research institutions who are involved in the research project.

FINDINGS FROM CONNECTICUT PROJECTS:

What To Do To Increase The Likelihood Of A Successful Partnership On Community Based HIV/AIDS Research

Individual case studies identified specific strengths and weaknesses associated with conducting CBR based on their particular research collaboration. However, there were recurrent themes across all of the models. The workshop on challenging collaborations and the IDU research participant workshop added further depth to our understanding of the collaborative research process of CBR. The following themes resulted and are our recommended *Guidelines for Successful Partnerships on Community Based HIV/AIDS Research*.

ESTABLISH OPEN COMMUNICATION.

Positive communication helps build trust and eliminates some of the problems with role confusion.

- Regularly scheduled meetings between research collaborators are essential, especially when there are multiple collaborators involved.
- Frequent, timely and respectful communication, between scientists, community partners and research participants on the status of the research project is critical to success.

BUILD TRUST BETWEEN RESEARCH COLLABORATORS.

Trust between the community partners and scientists is essential to successful research collaborations.

- Trust is something that often takes time to establish, but once formed, can result in many successful partnerships.
- The lack of trust is also a cause of failed research collaborations.
- Personal relationships often secure good will between partners.

CHOOSE SCIENTISTS AND CBOs CAREFULLY.

It's important to consider carefully with whom one chooses to collaborate because the future of the research project depends on the characteristics and qualities of the partners.

- Scientists should consider the infrastructure of the CBO with which they want to work and assess the extent to which the CBO needs assistance carrying out the research.
- The CBO's track record, its standing in the community, and the quality of previous collaborations should also be considered.
- The scientist's experience or capacity to engage in CBR should be considered along with the quality of previous collaborations.

SEEK ON-GOING COMMUNITY INPUT IN A VARIETY OF WAYS.

For CBR to be relevant and of benefit to the communities in which it is conducted, it must be undertaken with the support of and in collaboration with CBOs working with at-risk populations.

- Include community partners as members of the research team.
- Create a Community Advisory Board to provide feedback and advice on all aspects of the project.
- Include previous or potential research participants in gathering input.

ESTABLISH A LIAISON BETWEEN UNIVERSITY/INSTITUTIONAL ADMINISTRATION AND THE CBO.

Institutional policies may present barriers to CBR and a liaison who understands such structures can help navigate a CBO and collaborating scientist through policies.

- A liaison can help the project with the institutional review board (IRB) process.
- A liaison can navigate the project through institutional policies and procedures (e.g. Federalwide Assurance, Human Subjects Protections).

DELINEATE CLEAR ROLES FOR EACH PARTNER.

Clearly delineating the roles of each partner prior to the start of the project, in writing when appropriate, will help eliminate role confusion.

- Outline and define roles and expectations of the project, protocols, and all those collaborating, from leadership to frontline staff.
- The benefit to the community at large should be clear from the outset.
- Strengthen fiduciary relationships with community partners. The allocation of funds within projects should focus on research needs and service provision.

ESTABLISH A CLEAR PROJECT IDENTITY.

A clear project identity should be established from the outset to minimize role confusion.

- If a collaborative agenda is set, community partners can avoid the feeling of dual identity (i.e., balancing between doing research and being part of the CBO).
- It is important to distinguish between the research collaboration activities and the routine services provided by the individual CBOs.
- Research should be relatively non-intrusive and should not impede on the service provision of collaborating CBOs. Service provision should not impede on the conduct of the research, as well.

ENSURE EACH PARTNER HAS A VOICE.

In order to maintain a healthy partnership, each partner should have a voice in setting the agenda, creating the project identity, and constructing research objectives.

- Make sure that team building includes all interested partners involved, from front line providers to administrative staff and management and research participants.
- Throughout the research, the community partner should have shared input with scientists regarding research decisions. These include decisions about problem definition, study design, data collection and analysis, dissemination of findings, and resource allocation.
- Scientists and community partners should discuss expectations regarding acknowledgement and authorship in all publications based on the findings from the research project.

BRING THE PROJECT TO THE COMMUNITY.

It is important to recognize various characteristics of the community with whom you are working.

- Involve the community partners before the research begins. There should be participation from CBOs in the development of research proposals and theoretical frameworks.
- Develop an understanding of the socio-political structure of the community within which the research is being conducted as well as those within the community who are supportive/against the project.
- Ensure mutual benefit to all parties involved in the research (community and scientists). This allows for a feeling of project ownership by all parties involved.
- Tread lightly with large institutional names (e.g. A “Yale University Study”).
- Provide workshops or other forums that allow CBOs to turn intervention problems into research hypotheses.
- Consider if there are communities or populations not being reached by research because of language barriers, homelessness, etc.

DISSEMINATE FINDINGS FROM THE PROJECT.

Timely turnover of information is crucial so community partners and research participants are aware of the project outcomes for which they were involved, and steps can be taken to implement appropriate services, increase outreach efforts, and troubleshoot programmatic issues.

- Create a dissemination plan with quick, accurate, and varied methods prior to conducting research and ensure that all parties including research participants will be informed of and understand the findings regardless of the outcome.
- Establish a line of communication between scientists and community partners, and develop a protocol for dissemination of information. To aid this and other aspects of research, there needs to be an explicit understanding of the “chain of command” in each agency.

CONSIDER SUSTAINABILITY OF THE PROJECT.

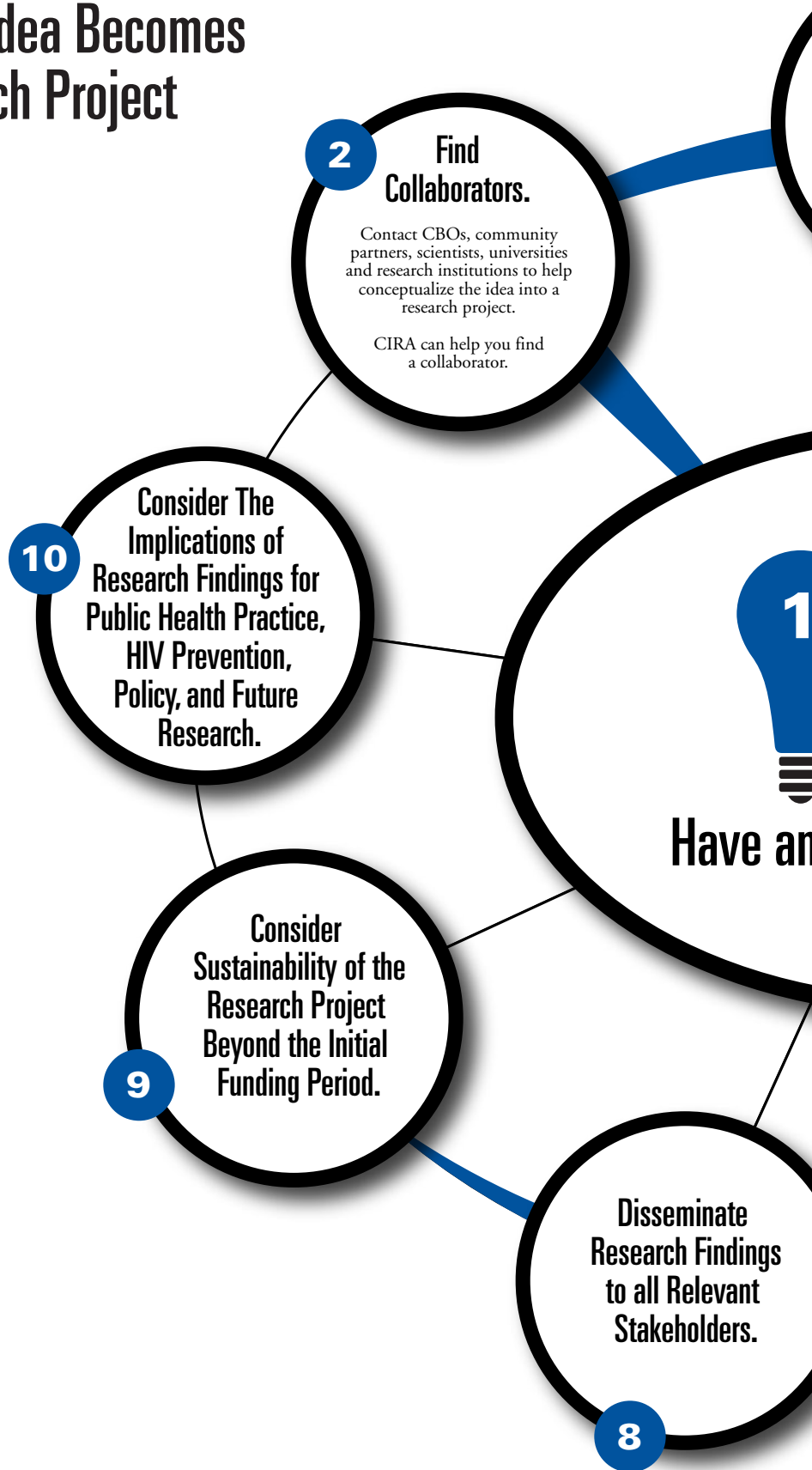
Sustainable research collaborations are important to maintain or improve the welfare of the community.

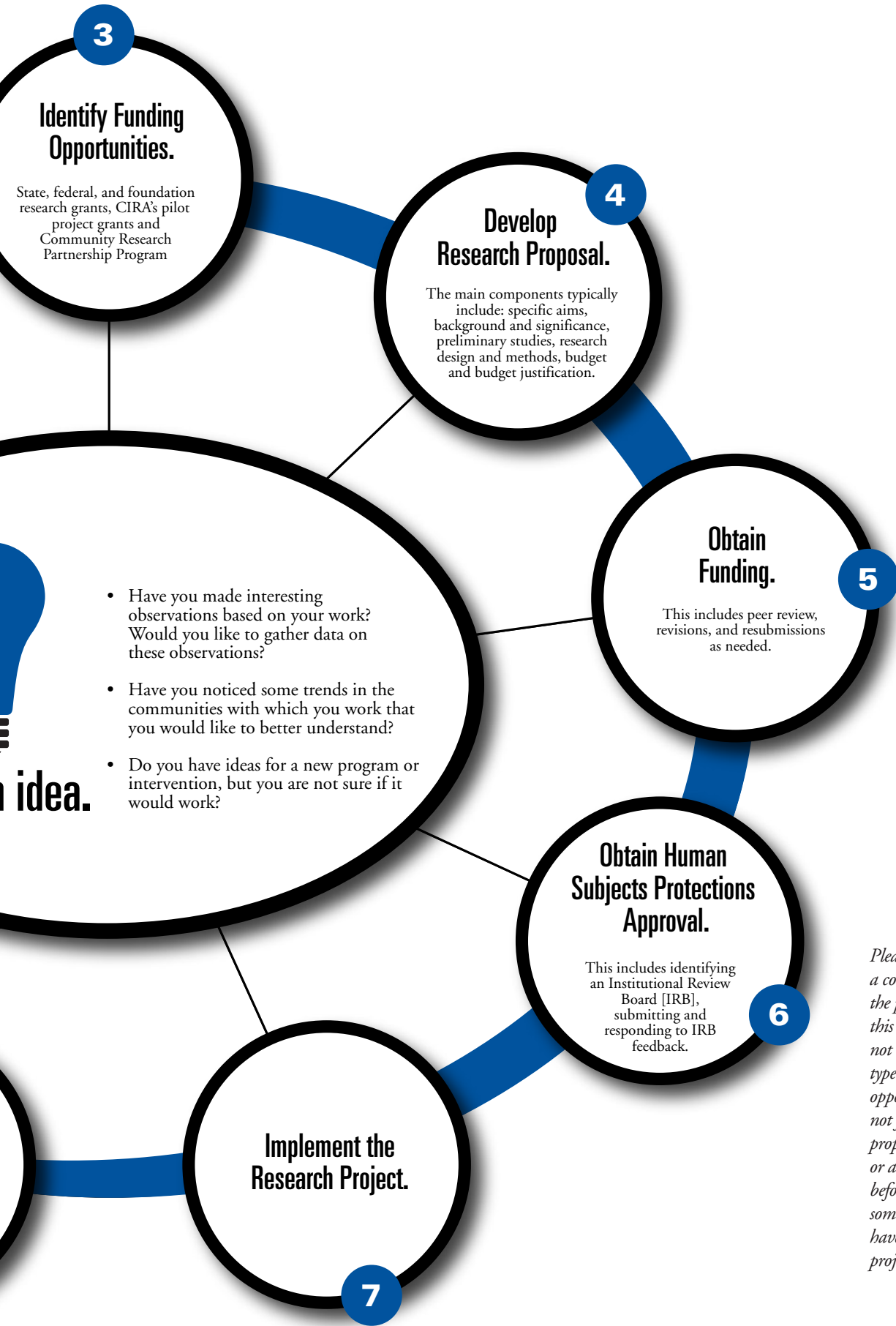
- Maintain continuity of leadership and commitment.
- Develop mutual respect, commitment, and trust. These should expand from interpersonal to institutional relations in order to achieve sustainability.
- Always keep records of lessons learned, especially around ethical and political concerns.
- Develop a plan for sustainability of appropriate aspects of the project (i.e. successful interventions).

How an Idea Becomes a Research Project

“The voices and lives of people in our communities, the organizations that provide services and support to make those lives richer, and the academic institutions that conduct research form a triangle to make those voices heard. But this is not a natural triangle, and it is only as strong as our abilities to work together. The foundation can only get stronger if the research makes it back to the community and the development of appropriate services for the population researched can be initiated by the CBOs. Under these conditions, collaborations work and I am forever grateful when given the opportunity to develop preventions for those that I hold closest in my heart.”

Mark Kinzly,
Community Advocate,
Research Associate





Please note: The flowchart represents a common order to this process, but the process does not always align with this exact order and each step may not be necessary depending upon the type of project. For example, funding opportunities may generate ideas not fully developed until the call for proposals brings partners to the table, or a sustainability plan is developed before findings are disseminated. Also, some kinds of research projects do not have to be sustainable (e.g. descriptive projects or needs assessments).

CASE STUDY I

The Hartford Community Alliance For AIDS Prevention (CAAP)

The Hartford Community Alliance for AIDS Prevention was a consortium of Hartford area agencies that worked together to conduct six federally funded research projects over a 10 year period.

COLLABORATING INVESTIGATORS:

HISPANIC HEALTH COUNCIL
Merrill Singer, Ph.D.

INSTITUTE FOR COMMUNITY RESEARCH
Jean J. Schensul, Ph.D.
Margaret R. Weeks, Ph.D.

HARTFORD DISPENSARY
Paul McLaughlin
Phillip Richmond

URBAN LEAGUE OF GREATER HARTFORD
Regina Dyton
Richard Gruber

LATINOS/AS CONTRA SIDA
Clara Acosta-Glynn
Manuel Magaz

AIDS PROJECT HARTFORD
Paul Botticello

HARTFORD HEALTH DEPARTMENT
Dalia Belliveau

FUNDING AGENCIES:

NATIONAL INSTITUTE ON DRUG ABUSE
Grant #: R18-DA05750 (COPE)
U01-DA07284 (COPE II)
R01-DA09224 (NEP Eval.)

CENTER FOR SUBSTANCE ABUSE TREATMENT
Grant #: H1N-TI00344 \ (CONNECT)

CENTERS FOR DISEASE CONTROL AND PREVENTION
Grant #: U65/CCU107678 (MAPP and MAPP II)

DATES:

1988 - 1997

PROJECT COPE 1988-1992

Preventing AIDS Among Injection Drug Users and their Sex Partners
Grantee: Institute For Community Research

ABSTRACT

The late 1980s showed an increase in HIV infection within urban communities, and a particularly high rate of risk among injection drug users (IDUs) and their sex partners. A common belief was that, unlike gay men, IDUs would be unresponsive to AIDS prevention education. This four-year, Hartford, CT-based study dispelled that belief while also examining the drug use patterns and HIV risk behaviors among IDUs and their sex partners. The project assessed their HIV risk, and offered HIV education, antibody testing and counseling. It also provided and studied the effects of an enhanced, culturally-specific HIV/AIDS prevention intervention aimed at African Americans and Puerto Ricans/Latinos in Hartford. The project developed a five-organization community based consortium that included both research and service organizations. COPE was part of the National AIDS Demonstration Research (NADR) project, one of 29 similar studies across the nation.

PROJECT COPE II 1992-1997

The Community Outreach Prevention Effort
Grantee: Hispanic Health Council

ABSTRACT

The Hartford Community Alliance for AIDS Prevention (CAAP), which was established in 1988 and administered Project COPE I, used lessons from that project to develop this five-year HIV prevention study that worked with active, out-of-treatment injection drug users and crack cocaine users in Hartford, CT. As part of a 22-city, national Cooperative Agreement for AIDS Community Based Outreach/Intervention Program, the Hartford study, COPE II, monitored the drug use, HIV risks, and prevalence of HIV infection among participants through interviewing, surveys and HIV antibody testing. It also tested the efficacy of HIV-risk reduction intervention programs, comparing a standard AIDS education program with culturally-targeted enhanced interventions for African Americans and Puerto Rican Latinos.

PROJECT MAPP and MAPP II 1992-1997

Minority AIDS Prevention Program
Grantee: Urban League Of Greater Hartford

ABSTRACT

To further expand services to African American and Puerto Rican drug users and their sex partners, the CAAP Consortium developed Project MAPP. This program offered intensive prevention case management to high risk individuals, and health education for risk reduction training to groups of high risk people primarily in institutional settings (shelters, half-way houses, supportive programs, etc).

HARTFORD NEEDLE EXCHANGE PROGRAM (NEP) EVALUATION 1994-1997

Effectiveness of Needle Exchange in AIDS Prevention
Evaluation Grantee: Hispanic Health Council

NEP Grantees: Urban League Of Greater Hartford, AIDS Project Hartford

ABSTRACT

This was a collaboration between researchers and service providers who were responsible for implementing the Hartford NEP. The evaluation involved tracking of syringes distributed through the program and assessment of risk reduction practices associated with IDUs' participation in NEP.

DESCRIPTION OF RESEARCH COLLABORATION

This partnership succeeded by developing an environment where commitment, communication, management, and sensitivity were valued ideals. The reputation of the researchers, Jean J. Schensul, Ph.D., and Merrill Singer, Ph.D., and their focus on community involvement and service in addition to research appealed to community members, allowing them to feel as though they were equal participants in the project. The establishment of a healthy relationship through regular community meetings between community members and scientists created a space of trust. The group was able to relay an influential uniform message to the greater community, research participants, and institutional forces. For instance, the police not only served to inform the public about the importance of HIV prevention, but also alleviated the threat of police harassment of the project. Community partners felt that being involved with a research effort helped to provide an organizing framework that shed light on the need for services and added credibility to efforts to expand upon existing services.

On a more specific note, research collaborators found that having regular meetings with all partners in attendance helped maintain a healthy partnership and uniformity of messages. Each agency involved took some form of leadership role in the project and therefore no single agency dominated. Meetings of upper management and front line providers were grouped into the following which provided opportunities for all involved in the project to have a voice:

- Steering committee made up of the executive directors of the consortium agencies. This group was responsible for major policy issues and working to prevent line staff problems through agency collaboration.
- Management team made up of managers representing each organization.
- Staff meetings with management teams, front line staff, PI, and the steering committee members.

LESSONS LEARNED

Project Objectives/Identity: There needs to be an overall project identity whose policies and protocols fit the tasks involved. If a collaborative agenda is set, collaborators can avoid the feeling of dual identity where they must waiver back and forth between assisting with research and being a part of the community. The two components should be woven together for the sake of creating a common project goal.

Ethical Considerations: One of the goals of Project COPE was to provide HIV testing. At that time earlier in the epidemic, there was some controversy about testing without availability of treatment. Ethical issues and social concerns may need to be discussed and addressed to receive support and agreement among collaborators.

Project Design/Feasibility: The project would have been more successful if it was designed to work within the community without disrupting the daily routines of service providers. In this case, research conducted within the clinical setting at times stood in the way of the clinical staff's daily tasks/responsibilities. Future collaborations should take this into account when designing project protocols.

Project Population: Researchers need to be aware of the characteristics of the population in which they are working. Project COPE dealt with a high risk population which encountered severe stressors.

Multiple Collaborators: Project COPE included many different organizations with diverse cultures and styles. While having a large number of collaborators adds particular challenges, it also adds potential for broad impact and benefits as well.

Leadership/Management/Governance: It is important to delineate each actor's role in the collaboration as well as to determine a common set of rules/guidelines to adhere to. With various representatives from each community partner on site, it was difficult for staff to determine whose organizational rules to follow/which rules applied. Furthermore, written records of all policies and decisions should be kept.

“ This was an effective collaboration between researchers and clinicians.”

Phil Richmond,
Hartford Dispensary

“ Community collaboration is not easy; it takes a load of work, and a great investment of time. The pay off that makes it worth it is the long-term relations that are developed, the quality of the data collected, and the certainty that the new knowledge that is gained will be put to directly into use in the service of the community.”

Merrill Singer,
Ph.D., Hispanic Health Council

CASE STUDY II

New Haven Needle Exchange Program Evaluation Project

PRINCIPAL INVESTIGATOR:

Edward Kaplan, Ph.D., Yale School of Management;
Robert Heimer, Ph.D., Yale University School of Public Health

COMMUNITY CO-INVESTIGATORS:

Elaine O’Keefe, New Haven Health Department,
Alvin Novick, Ph.D., and Sher Horosko, Mayor’s Task Force on AIDS

PARTNERS:

New Haven Health Department, New Haven Mayor’s Task Force on AIDS, Yale University Researchers

FUNDING AGENCY:

Needle Exchange Program:
1990-1992 – City of New Haven, State of Connecticut.
1993-1995 – City of New Haven, Robert Wood Johnson Foundation, State of Connecticut
Yale Evaluation:
1990-mid 1992 – Yale Department of Internal Medicine
Mid-1992-1995 – National Institute on Drug Abuse, Robert Wood Johnson Foundation

GRANT #: R01-DA07676

DATES: 1990-1995

ABSTRACT

Relying primarily on an anonymous syringe tracking and testing system, the evaluation demonstrated that the New Haven Needle Exchange Program (NEP) reduced the circulation time and prevalence of needles contaminated with HIV- and hepatitis-infected blood. The data were incorporated into mathematical models that estimated, most conservatively, a rapid one-third decline in the rate of new HIV infections. At the same time, programmatic data revealed no encouragement of injection drug use or unsafe injection behaviors and an increase in the entry of drug users in substance abuse treatment programs.

DESCRIPTION OF RESEARCH COLLABORATION

This partnership evolved from participants in the City of New Haven Mayor’s Task Force on AIDS, a task force which had been fighting to improve the health of injection drug users since the mid 1980s, through the leadership of Elaine O’Keefe from the New Haven Health Department. The original goal of the research collaboration was to change laws banning the sale of needles without a prescription, a change that would allow injectors to have access to uncontaminated needles. Eventually the focus shifted to the development and implementation of a pilot NEP that took three years of state lobbying before approval. The pilot NEP included an evaluation component, which was not to interfere with the operations of the NEP, frighten participants, or overburden the program, and was to be completed within a year.

Collaborators on the project included, Yale scientists, Edward Kaplan, Ph.D., and Robert Heimer, Ph.D., who were funded by NIDA, and community partners from the Mayor’s Task Force on AIDS and the New Haven Health Department. All collaborators were advised to refrain from referring to the program as “needle exchange.” Rather, they called their activities – essentially a mobile syringe exchange program – a new system for tracking syringes and testing for HIV epidemics. Yale scientists were responsible for the research component while services provided by the NEP were funded by the New Haven Health Department. Within one year (1990-91), the research project reported a 33% decrease in infectious syringes.

Community partners in the research project cited good public health practice and a determination to save lives as their motivation for being involved. The New Haven Health Department did not consider this a research project, even though it was. The NEP – and not the evaluation of it – was what was important. The success of the research collaboration depended on mutual commitment and passion for the NEP and its evaluation. Commitment of the service recipients/ members of the community being targeted is essential for a NEP. In this case, the NEP had the commitment of IDUs as well as those staffing the needle exchange van. The research collaboration also benefited from a sense of equality amongst collaborators. With a common goal of wanting to protect the NEP, everyone had a distinct role and some control. It was not a top down initiative; rather researchers were seen as individuals carrying equal weight with every other community partner and not as Yale University in opposition to or competition with the community.

Although the research collaborators worked together successfully, there were several barriers within the broad community at large. Specifically, various racial and ethnic communities, drug treatment advocates, and local government officials varied in their levels of support and perspectives for the NEP. Furthermore, the history of mistrust between disenfranchised communities in New Haven and researchers created an air of suspicion from the community.

LESSONS LEARNED

Social-Political Climate: There needs to be an understanding of the socio-political climate of the community one is working with as well as of who within the community supports/opposes the project. Understanding the racism and socio-political context prior to working within a community may provide the researchers with insights needed to establish a sense of common trust.

Equal Voice/Equal Consideration: The perspective of community participants and partners needs to be taken into consideration at all times. There needs to be a sense of mutual respect, leadership, and recognition for each contributor's efforts. Some community partners noted their disappointment with never receiving the type of recognition (e.g. credit for establishing the first legal syringe exchange program in the country) that researchers receive for these programs.

Project Design: The evaluation will be more successful if it is designed in a manner that does not impede the services provided by the program. Rather, an unobtrusive evaluation may serve the needs of the program. Furthermore, a clear delineation of research and programmatic funding is helpful to avoid confusion among the different funding sources that may have different restrictions.

Governance/Sustainability: Sustaining commitment to the research collaboration is important. Collective decision-making, having outlets to discuss problems/frustrations, and awareness from the start of the mutually beneficial aspects of the partnership can help to sustain the collaboration. Additionally, there needs to be structure and institutional links to the research collaboration as opposed to merely a network of personal relationships in order for the project to continue to thrive.

Dissemination of Information: The community partners in this project expressed the need to have timely turnover of information back to the community so that steps could be taken to implement appropriate services, increase outreach efforts, and/or troubleshoot programmatic issues. Furthermore, the community needs to understand the outcome of the project even if it is not the outcome they hoped to achieve. However, if research shows there are problems with the program, it has to be presented in a way that does not embarrass those involved.

“ One of the more gratifying aspects of the research was the opportunity to explain the science to the non-scientists doing the hard work of HIV prevention.”

Robert Heimer,
Ph.D., Yale University

“ It was an honor for me as a community participant to have been invited to participate in Case Study II. The experience and collaboration with Yale University, CIRA, and the community was very rewarding and meaningful to all of us involved, especially the New Haven Needle Exchange Program. Thank you very much to the late Dr. Alvin Novick for his commitment and leadership to the New Haven Needle Exchange program.”

Dominick Maldonado,
New Haven Health Department,
Needle Exchange Program

CASE STUDY III

Connecticut Women's Health Project

PRINCIPAL INVESTIGATOR:

Jeannette Ickovics, Ph.D., Yale University

FUNDING AGENCY:

National Institute of Mental Health

PARTNERS:

Associates in Family Health, Bridgeport Hospital, Bridgeport School-based Health Clinics, Charter Oak Terrace – Rice Heights Community Health Center, Fair Haven Community Health Center, Hartford Hospital, Hospital of Saint Raphael, Park City Center for Ob-Gyn, Planned Parenthood of Connecticut, Yale-New Haven Hospital Women's Center, Yale University Researchers

GRANT #: 5R01MH061175-05, and P01MH/DA56826, Intervention to Reduce HIV/STD Risk in Teen Pregnancy

DATES: 1997 – 2006.

This “case study” is drawn from a study conducted in collaboration between community health centers/hospital-based health care centers, Yale University and other researchers.

ABSTRACT

The behaviors that put adolescent women at risk for pregnancy also put them at risk for HIV and other sexually transmitted infections (STIs). This research draws from and integrates theories of self and identity to examine adolescents' motivations around pregnancy and disease prevention through (1) A multi-site longitudinal study of a cohort of pregnant adolescents (n=203) and a comparison cohort of non-pregnant adolescents (n=209) which was conducted over 18 months in health clinics throughout Connecticut -- data were collected through structured interviews and semi-annual STI testing; and, (2) A cross-sectional study of sexual partners and parents of these adolescent women. Findings from this study demonstrate that adolescent women do not perceive their own risk for STIs, HIV and pregnancy. Pregnant teens are four times less likely to use condoms to prevent an STI than non-pregnant teens and are two times more likely to have an STI one year after giving birth.

DESCRIPTION OF RESEARCH COLLABORATION

In 1989 the Connecticut Women's Health Project began as the New Haven Women's Health Project. The first funded study was designed to identify the determinants and consequences of HIV testing for women at three community health care centers in New Haven. After the scientific documentation that AZT taken during pregnancy could significantly reduce the risk of HIV transmission from mother to child, another early study examined HIV counseling and testing, specifically during pregnancy. Scientists noted that more than one third of the pregnant women seen at prenatal care sites throughout New Haven were ages 12 to 19, which led to a new initiative. Thus, the team collaborated with 12 clinical sites throughout Connecticut to conduct an observational study including more than 400 pregnant and nonpregnant adolescents to identify risk and protective factors during pregnancy and up to 18 months postpartum. After documenting pregnancy as a time of substantial risk – but also as a window of opportunity for prevention – the team moved from descriptive studies to intervention studies. In September 2004, they completed recruitment for a large randomized controlled intervention designed to reduce risk during pregnancy for teens and young women. CenteringPregnancy is an innovative model of group prenatal care that integrates HIV and STD prevention as part of routine care in a model that is fully sustainable.

In CBR, there needs to be a clear definition of the community partners from the outset. In this case, the community partners were defined as a network of community based health care centers, health-care providers, and patients. The success of this model rested on respect, communication, commitment, and trust between staff and community partners. From the outset, research was conducted with and not imposed upon the community. Because the projects were conducted in collaboration with healthcare centers, it was extremely important for researchers not to place an added burden on the staff members who were not working directly with the project, thus taking away from their routine duties as healthcare providers. Personal relationships secured good will between partners. The staff, understanding the risks faced by study patients, were committed to mitigating those risks. Furthermore, the project was designed to improve patient care and maintain confidentiality, which set up an environment of trust among the project partners.

LESSONS LEARNED

Project Identity: It is very important to distinguish between the research and the routine services provided by the community partner (in this case the health care center). The health care center may be perceived as the research institution and receive questions regarding problems arising in the research that health care center staff are unable to address.

Project Design: The research may be more successful if it is designed to fit into the system of care delivery. Patients can be intimidated by research, fearing a loss of access to normal clinical services if they do not participate in the project. It is important to make sure that patients are informed and understand the circumstances behind the project and their rights to care, regardless of their study participation. The project should also be designed to “minimize intrusiveness and maximize benefit” so as to not hinder the daily routines of the collaborating institutions and the frontline clinic staff.

Dissemination of Information: Research collaborators in the project noted the importance of having a dissemination plan early on in the process. This was important for this series of projects for two reasons. First, since patients were getting tested for sexually transmitted infections (chlamydia and gonorrhea) as part of the study, it was important to have a plan for these test results (especially if positive) to go from the lab to the research staff to the health care center providers and ultimately to the patients in the most timely and efficient manner. Through experience, the partners determined that this happened most effectively when there was one key person at the health care center to contact who then took responsibility to inform the patient and have her return for treatment. This is an interesting case of the importance of setting up explicit communication patterns so that disease identified by the research collaborators could then be quickly and responsibly treated by the health care center collaborators. All of this must be done in a manner that protects patient confidentiality and follows state guidelines regarding reporting of infectious diseases to the Connecticut Department of Public Health. Regarding communication to a broader level, the project successfully disseminated quarterly newsletters and packets containing information compiled on community resources including material prepared for health care center partners. Resources for dissemination activities were integrated into research staff responsibilities.

Communication Amongst Partners: Partners pointed out how important it is to get input from the staff and the potential research participants during the development of the research proposal, theoretical framework, and structure of the intervention. Grant ideas should be developed in partnership so that all parties are participating from the onset. To go to the collaborating community partner after the grant has been funded may be too late; it is optimal if the community partner is involved from the beginning.

Mutual Benefit: Some community partners expressed that the research be conducted in a manner that satisfies both the scientists and community partners. The financial stability and capacity of the CBO after the study should not be less than it was prior to the study. CBOs should also be included as fiduciaries. Some funds were directly available to each health care center site (e.g., nursing staff, funds for educational materials). It is important that the distribution of funds be fair and representative of effort and contribution among those involved in the research collaboration. However, no tension was identified in regard to this imbalance.

Research Sustainability: There was a need for help with research-oriented thinking among community partners. One recommendation called for the provision of workshops on how to turn an organization’s problems into a research hypothesis. In order to sustain a climate of community based research, collaborators noted the importance of expanding the trust built on personal relationships to a larger institutional trust. It is also important to have a high level of commitment where researchers jump into the project for the “long haul.”

“ Good community based research is research WITH the community, not ON the community.”

Jeannette Ickovics,
Ph.D., Yale University

“ CBR is effective when you have a partnership of trust and collaboration in which we are all winners.”

Katrina Clark,
M.P.H., Fair Haven Community
Health Center

CASE STUDY IV

HIV Prevention in High-Risk Drug Use Sites: Project RAP (Risk Avoidance Partnership)

PRINCIPAL INVESTIGATOR:

Margaret R. Weeks, Ph.D.,
Institute for Community Research

PARTNERS:

Peer Health Advocates (PHA)
from within the community

FUNDING AGENCY:

National Institute on Drug Abuse

GRANT #: 5 R01 DA013356

DATES: 2001 – 2005

ABSTRACT

Reaching active drug users to provide them with information and materials to support HIV prevention has often been hampered by the inability to disseminate harm reduction information and model prevention behavior in locations where individuals are using drugs and where risky exchanges of syringes and works actually occur. The Risk Avoidance Partnership (RAP) project is measuring HIV prevention adoption by drug users and their social networks in Hartford, CT. Using a harm-reduction framework and working with active drug users - peer leaders trained to be peer health advocates - in the settings in which they carry out their daily activities, the study is introducing peer developed harm reduction messages and products designed to promote risk prevention. Through surveys, ethnographic observation and tracking of peer-led intervention activities, the study evaluates the efficacy of this prevention approach. The project also initiated the development of a drug-user-led community advocacy group as a vehicle for addressing issues of concern to the drug using community. The study is based on findings from “Study of High Risk Drug Use Settings for HIV Prevention” (see <http://www.incommunityresearch.org/programs/highrisk.htm>).

DESCRIPTION OF RESEARCH COLLABORATION

The motivation for community participation in this project was two fold: financial incentives coupled with a desire to contribute to the community. There was a feeling that someone was reaching out to the community for once: “I like that people come knocking on my door instead of me knocking on theirs.” Because community partners (drug users) were involved early on in the process, the project was able to screen and successfully recruit over 100 Peer Health Advocate (PHA) trainees. Community partners felt needed, providing protection to the scientists who were out of their element when hanging out in high drug traffic neighborhoods. The feeling of having equal responsibility and significance in the project was important for the collaboration.

Part of the project’s success stemmed from the fact that community partners (drug users) were seen as part of the solution and not the problem. Not only did this help to empower community partners, but it helped to reduce the demonization of drug users. Furthermore, community partners expressed an improvement in their sense of self and how they relate to their communities. The research collaboration was also successful because research was not the only objective; rather, it was seen as part of a broader effort to improve the community. The target of the intervention – educating drug users – was important to both community partners and researchers.

LESSONS LEARNED

Participant Vulnerability: While community partners (i.e. community residents) saw themselves as mediators between researchers and the community, they expressed reservation in exposing themselves and their drug use to the opportunity for public scrutiny. Researchers should develop a system of support when hiring active or former drug users.

Sustainability: It was difficult to maintain project focus and momentum and to keep community partners engaged for a long period of time. This may be partly attributed to the fact that the project could not pay the PHAs sufficiently and for a sustained period of time.

Dissemination of Information: There was some concern with getting community partners to adopt a style that was well suited to communicating a primary health message. It was also difficult to confirm that the information being distributed by community partners was in fact diffusing through networks.

Project Population: There is a need to consider if there are communities/populations not being reached by the research intervention. In this case, homeless and Spanish speakers were harder to reach.

In addition, women, young drug users, and “pill” (i.e. oxycontin) users were not well represented.

Feedback: PHAs expressed the need for opportunities to vent frustrations, difficulties, and have people listen to them. They also wanted their outreach role to become more permanent and offer stable income in the form of a job.

Safety of Participants: Police harassment was an issue for those involved in the project.

Future collaborations should consider these and other issues of safety.

“ Partnering with active drug users to develop and test the RAP peer-delivered intervention showed the importance of building deep connections between researchers and target audiences for model programs to succeed.”

Margaret R. Weeks,
Ph.D., Institute for
Community Research

“ Being a Peer Health Advocate inspires you to give back to the community and take your self-esteem to a whole ‘nother level.”

Larry Lovette,
RAP Peer Health Advocate

“As scientists in search of new knowledge in HIV prevention research with drug users, we have learned the lesson over and over again that we must put aside our judgments and preconceptions and provide ample opportunities for drug users to share their experiences with us. After all, when it comes to use of drugs and its associated HIV risk, they are the experts.”

Kaveh Khoshnood,
Ph.D., Yale University

THE EXPERIENCE OF IDUs IN CBR

To complement the lessons learned from the case studies, the CR Core invited researchers who specialized in IDUs and “veteran” IDU research participants from various projects to a workshop. The main purpose of the workshop was to provide a space for a dialogue on CBR with community partners and the CR Core, and to hear and document the experiences of IDUs in research projects. The key highlights from the workshop were used to develop the guidelines for successful CBR.

KEY HIGHLIGHTS FROM THE WORKSHOP

Project Objectives: A clear-cut description of the study, its goals, and the roles of all persons involved should be established and communicated to all researchers, project staff and participants. The objectives should include sharing the research findings with all participants and throughout the community that might benefit from them.

Sustainability: Research field staff should communicate how the project might continue within the community and what opportunities may arise for participants’ further involvement in additional studies or research collaborations.

Incentives and Ethical Considerations: While money is an incentive to recruit participants, some may use this money to buy drugs. Fewer participants may get involved without monetary incentives. The researcher must be aware of the balance between the need to include research participants and the possibility of continuing drug use.

Role of Research Field Staff: The role of the research field staff needs to be established early in the research timeline and clearly stated. If the research field staff are able to build a rapport with the community prior to the collection of data in an interview, the project has a higher likelihood of success. Many participants need compassionate, good listeners who are not just “using them” for research purposes, and who treat the participant with dignity. Some research field staff develop a relationship with participants and often act as a resource (e.g. participants contact researcher for a referral, support, questions remotely related to the project). Research field staff also need to understand the participants’ different levels and stages of addiction.

Quality of Research Field Staff: The ‘quality’ of the interviewer must be consistent throughout in order to achieve consistent findings. Many participants enjoy the rapport with the research field staff, and it is important that the staff members do not appear to be there just to “gather information.” Research field staff need to be knowledgeable of the research process. This includes being able to explain the study in a way that is understandable to all participants, and the need to be explicit in asking questions to fully understand participant response. If research field staff are going to refer a participant to a treatment center or other social services, they need to make a plan to do so and follow-up.

Dissemination: Research participants want to know study findings, and not wait years to hear them. This contributes to the idea that participants are not merely ‘used’ for information. The research findings can be disseminated to communities of interest via local conferences that may include community partners on the project. Outreach workers can play a crucial role in dissemination.

CHALLENGES TO COLLABORATIONS IN CBR

To complement the lessons learned from the case studies and the workshop on IDUs involved in CBR, the CR Core invited CIRA scientists and project staff involved in particularly challenging collaborations, including those faced with university barriers to CBR, to a workshop. The main purpose of the workshop was to provide a space for a dialogue on such challenges and barriers and to learn from these experiences. The key highlights from the workshop helped to inform development of the guidelines for successful CBR.

KEY HIGHLIGHTS FROM THE WORKSHOP

Expectations: It is important that there is a common agreement, possibly in writing, before the research begins, about the roles and responsibilities of each participating entity (CBO, university, etc.). On one project, scientists felt that their community partner was redefining the researchers' role in mid-stream such that they became responsible for aspects of a project beyond the scope of what they had originally thought they were to do.

Clear Definitions: Roles and responsibilities need to be clearly defined. Some scientists felt that they were asked to go beyond the goals of the research project; the scientist and the community partner had differing views on the definition of "monitoring and evaluation."

Improved Communications: There needs to be an established line of communication between the scientists and the community partners, and a protocol for dissemination of information between scientists and CBOs. To aid this and other aspects of research, there should be an explicit understanding of the "chain of command" in a CBO.

Strength of Organization: Many CBOs have limited infrastructures, related to difficulties in organizing and carrying out research. Often, the CBO needs more help in carrying out the research than the scientist anticipated. For example, one scientist found that due to disorganization on the part of the CBO, consent procedures were not adequately completed. Health Insurance Portability and Accountability Act (HIPPA) privacy rules need to be maintained.

Research the Organization: Before scientists begin work with a CBO, it is important for them to investigate the CBO's track record, including the quality of its previous collaborations.

Know When To Cut Your Losses: There may come a point in time when it does not make sense to continue a project, due to insurmountable problems between the scientist and the CBO; this needs to be recognized, acknowledged, and addressed.

University Barriers: University policies may present barriers to CBR. High indirect cost rates associated with some subcontracts and the complex process of obtaining IRB approval for research projects are challenging for CBOs. A liaison who understands institutional structures and can navigate a CBO and collaborating scientist through the IRB process and institutional policies and procedures may be helpful.

"CIRA has developed important links throughout the local community with current and former active drug users, showing itself to be committed to the principle of community-based research. A new level of trust and communication is beginning to really show itself on the streets. These Guidelines will help strengthen that work."

Ed Leduc,
Community Advocate

PUBLICATIONS BASED ON RESEARCH FROM CASE STUDIES

Below is a collection of publications based on the research from the case studies included in these Guidelines. This is not meant to be a comprehensive list. If you would like more information on findings from these projects or other CIRA affiliated projects, please call (203) 764-4333 or visit www.yale.edu/cira.

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This work has been supported by the Center for Interdisciplinary Research on AIDS (CIRA), through its grant No. P30 MH62294 from the National Institute of Mental Health, Michael Merson, M.D., Principal Investigator.

