Engaging communities and institutions in HIV prevention research

Process: communities remain intimately engaged throughout data collection, analysis, and interpretation phases
Outcome: communities play significant roles in mobilizing the knowledge attained in CBPR projects for social change

How a CBPR can be helpful in your research:
- Relevant and Community Advisory Board member
- Serve as a source of feedback and wisdom
- Serve as a source of leadership and wisdom
- Provide technical, developmental, and strategic advice
- Provide knowledge about community and situation
- Help early to pay attention to specific ethical issues
- Suggest the research process and data analysis
- Facilitate delayed public and data availability
- Improve research credibility
- Help to validate and inform the needs of the community

Chronology of Community Involvement in HIV/AIDS Research:
- 1992-2010: Community care and prevention system.
- 2010-2015: How to develop collaboration with the community
- 2015-present: How to develop collaboration with the community

How to develop collaboration with the community
HIV Prevention Ethics Institute
Engaging communities and institutions in HIV prevention research
• Most of HIV research occurs in communities of color
• Engaging diverse communities represent a huge challenge for researchers
• Participation by ethnic minorities in health-related research is a concern because it creates health disparities
• Ethical engagement of communities of color present challenges
The emergence of HIV/AIDS brought a lot of activism and letter-writing, media campaigns and lobbying. Sucessed not just in changing the U.S. drug approval to how research on HIV/AIDS will be conducted, the main complain was that the HIV infected/affected community was not being integrated in decisions about regulations, services and research. These changes resulted in the creation of the Community Advisory Boards (CABs). See more at: [actupny.com/actions/index.php/the-community](actupny.com/actions/index.php/the-community).
Chronology of Community Involvement in HIV/AIDS Research

- 1987-The first AIDS clinical trial group (ACTG) was established
- The National Minority AIDS Council was established
- 1989- ACT-UP (AIDS coalition to unleash power) attended a meeting -uninvited- to voice community concerns
- 1990-Community representatives were invited to ACTG and formed the first CAB network
- 1998- Model regional training for communities and researchers
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Definitions
Shared Values
Multiple perspectives

Imaginary communities
Model

Community

CAB

Researchers

CABS
- They help to create a safe community
- Researcher-Community Partnership
- Helps to reduce health disparities
- Help to inform the research process by using "voices" in the subject matter, population and community context.
- CAB is a key component for a successful project.
The CBPR Model

Emphasize the participation, influence and control by non-academic researchers in the process of creating knowledge and change. Drawing on the traditions of action research, participatory action research, and participatory rural appraisals.
Process: communities remain intimately engaged throughout data collection, analysis, and interpretation phases

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CABS

- They help to create a real community-researcher (academic) partnership
- Help to reduce health disparities
- Help to inform the entire research process by using "experts" in the subject matter, population and community context.
- CBPR is a key component for a successful project
How a CAB can be helpful in your research:
Researchers and Community Advisory Board members:

- Serve as a source of leadership and partnership
- Review protocols (development and implementation)
- Provide knowledge about recruitment and retention,
- Help you to pay attention to specific ethical issues
- Monitor the research process and data analysis
- Human subjects safety/liability
- Help to educate and inform the rest of the community
How to recruit your CAB

Ethical Review
- CABs need to be involved in the IRB process
- Be open about challenges and vulnerabilities
- CABs can influence and change IRB process

Community Engagement
- Immerses yourself in the community
- Identify community needs and interests
- Be clear about the purpose and goals of the community engagement effort
- Become knowledgeable about the community
- Establish relationships and build trust, seek commitments from CEOs, stakeholders
- Allow self-expression
- Partner with the community: don’t be a helicopter researcher
- Be flexible and ready for long commitment
- Your study should be relevant to the community

Capacity Building
- Assess and sustain community structure
- Assess and advocate for resources
- Plan for sustainability

Social Action/Action Research
- Research in HIV/AIDS should not stop just there.... Share results with the community
- Implement findings
- Engage in social change
- Be open to new research issues that the community needs

Research Process
- Work closely with CAB in the entire research process (recruitment, protocol, development, data, analyses)
- Agenda development should be a dual effort
- Joint data ownership
- Redefine the role and purpose of CAB
Community Engagement

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Recommendations for Community Involvement in National Institute of Allergy and Infectious Diseases HIV/AIDS Clinical Trials Research

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