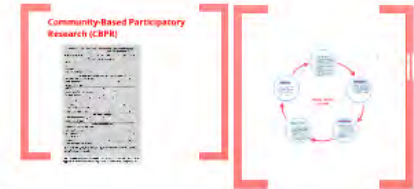


Process: communities remain intimately engaged throughout data collection, analysis, and interpretation phases
Outcome: communities play significant roles in mobilizing the knowledge attained in CBPR projects for social change



- How a CABS 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



Engaging communities and institutions in HIV prevention research



- How HIV research is often conducted**
Engaging diverse communities represents a huge challenge for researchers
- Participatory (by ethics committees, health or state research is a core value because of broader health disparities)
 - (Oral) engagement of communities of color persons (ethics)



Chronology of Community Involvement in HIV/AIDS Research

- 1985-The first AIDS clinical trial group (ACTG) was established
- The National Minority AIDS Council was established
- 1990-ACTG (AIDS coalition to launch power) attended a meeting, uninvited - to voice community concerns
- 1990-Community representatives were invited to ACTG and formed the first CAB network
- 1994- Similar regional training for communities and researchers
- 2007 Establishment of community partners



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Engaging communities and institutions in HIV prevention research

Chronology of
Involvement
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

HIV and Community

History about the CABs

ence of HIV/AIDS brought a lot of activism and
y not just in the us but in Europe, filled with
, letter-writing, media campaigns and lobbying
succeeded not just in changing the U.S drug approval
o how research on HIV/AIDS will be conducted
main complain was that the HIV infected/affected
community was not being integrated in decisions about
ications, services and research
e changes resulted in the creation of the Community
sory Boards (CABs)
actupny.com/actions/index.php/the-community



CABs ...the beginning



You Tube

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
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- 1998- Model regional training for communities and researchers

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Definitions

STANDARD DEFINITION



STANDARD DEFINITION



A close-up photograph showing five hands stacked on top of each other on a light-colored wooden surface. The hands are of different skin tones and are wearing various sleeves: two dark grey business suits with white cuffs, and two light blue ribbed sweaters. The central hand is a darker-skinned person's hand. The text "Shared Values" is written in a blue serif font across the middle of the hands.

Shared Values



Multiple
perspectives

Imaginary communities



Multiple
perspectives

Imaginary communities

Transnational
Communities



Communities

Internet communities

community

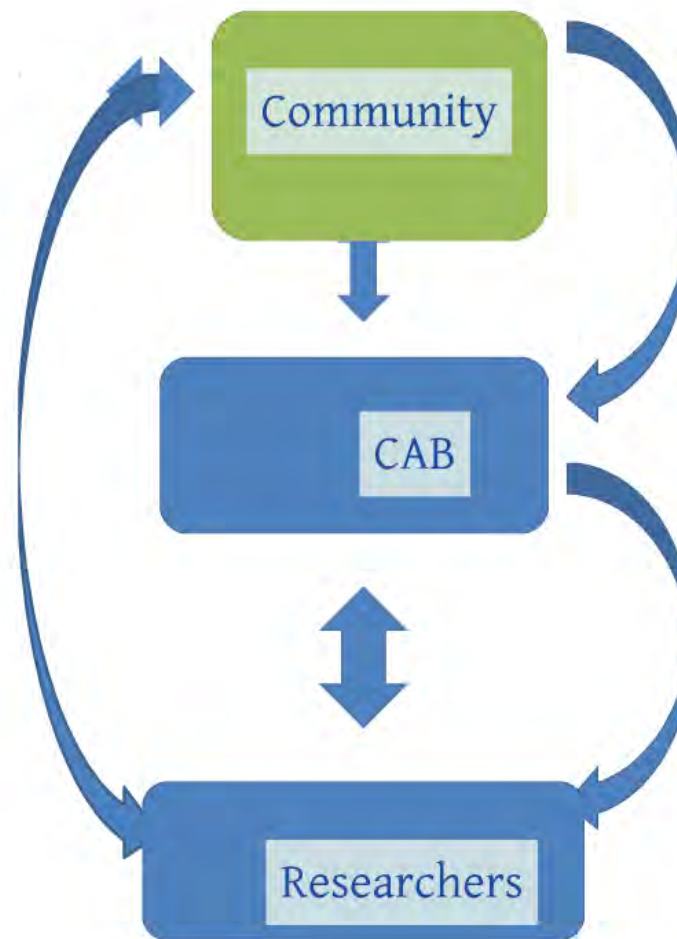


A diagram illustrating the CABS system. A large blue circle is centered on the page. Inside this circle is a light blue rectangular box containing the text "CABS" in a dark blue serif font. To the left of the large circle, a blue arrow points from a smaller blue circle towards the large circle. The smaller circle on the left contains a small, partially visible image of a group of people. In the top right corner, outside the large circle, is a light blue rectangular box containing the word "community" in a dark blue serif font. A thick blue line curves across the bottom of the large circle, and a solid blue square is located in the top right corner of the image.

CABS



Model



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

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.

community

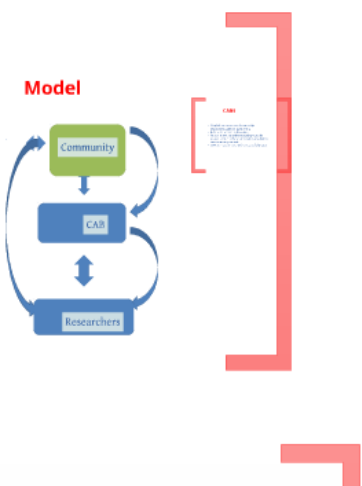


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CABS

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 CAB can be helpful in your research
Researchers and Community Advisory Board

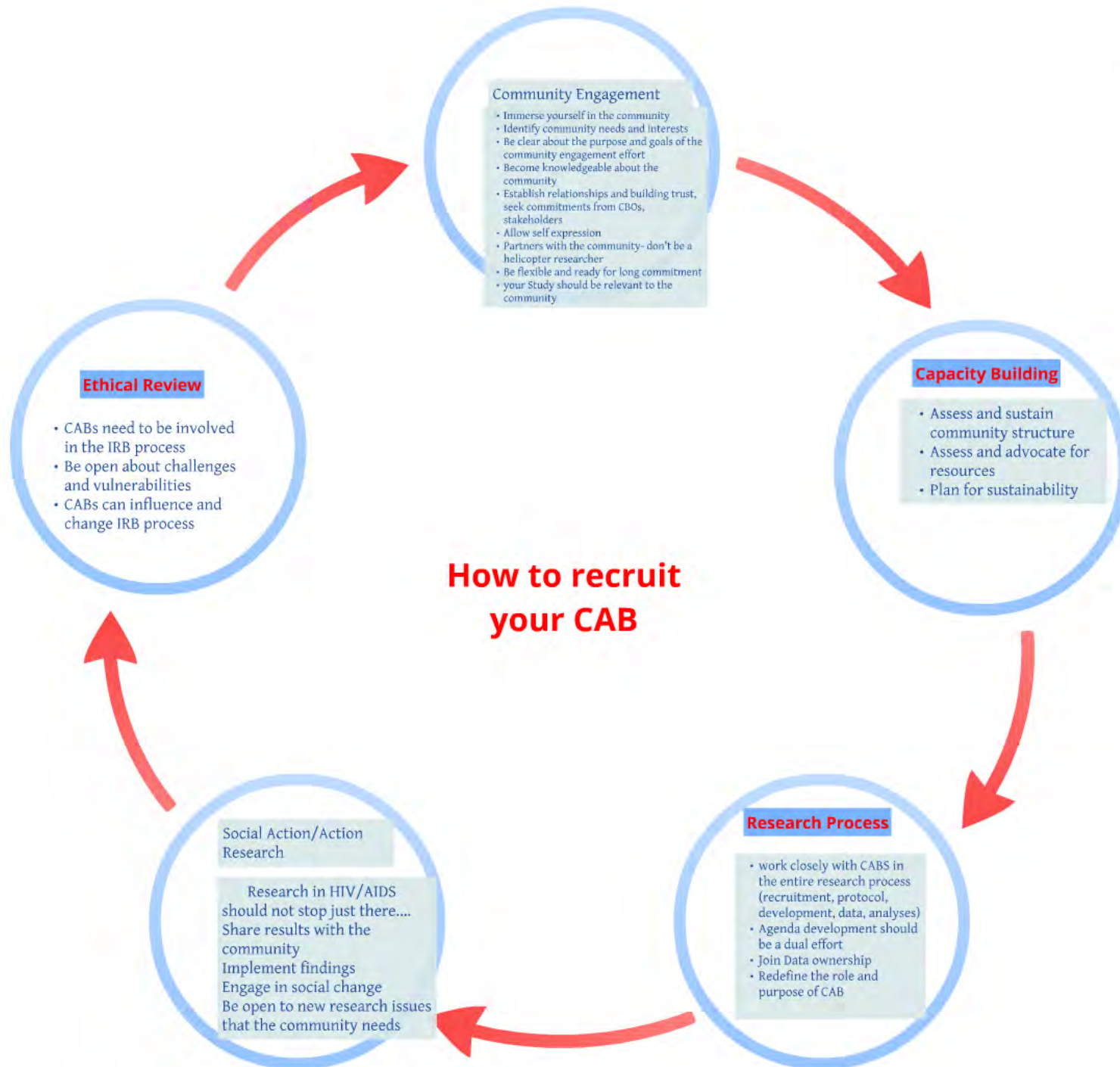
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How a CAB can be helpful in your research

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Community Engagement

- Immerse 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 building trust, seek commitments from CBOs, stakeholders
- Allow self expression
- Partners 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



Research Process

- work closely with CABS in the entire research process (recruitment, protocol, development, data, analyses)
- Agenda development should be a dual effort
- Join Data ownership
- Redefine the role and purpose of 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



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

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



February 2009

HIV Prevention Ethics Institute



Engaging communities and institutions in HIV prevention research

Chronology of
Involvement
Research

