Presentation on Community Partnership Guidelines

DPHS/CRA Workshop
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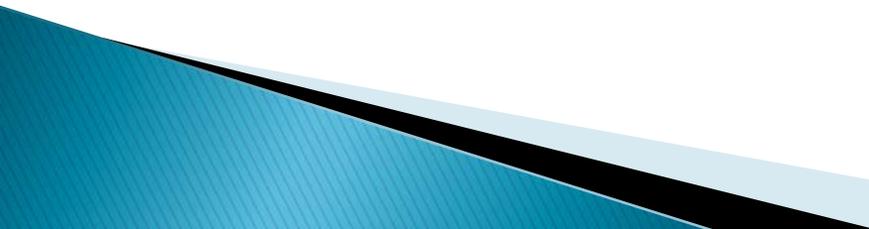
Introduction to Community Partnership Guidelines

- Research in and with communities
- Partnerships of researchers and NGOs/CBOs, Residents
- This workshop focuses on university based researchers and NGOs/CBOs, Residents
- Primary effort to reduce health disparities and inequities.
- Research can be basic or applied, individual or multi-level focused, and social/behavioral, epidemiologic or laboratory-linked.
- Research should be desirable, feasible, acceptable, appropriate, tailored, doable, and with describable potential or actual positive outcomes.

Community Research Partnership Guidelines

- Involvement of partners in the research process
- Developing an understanding of, respect for and commitment to the community where research takes place
- Relevance and benefit of the research
- Effective communication among partners
- The ethical conduct of research
- Recruitment in community settings
  - Engaging community-based organizations (CBOs) and the broader community in the recruitment process.
  - Recruiting prospective participants in the research
- Capacity-building, resource sharing and sustainability

Partners

- It is during the pre ART period in HIV infection. You are working with an organization in Hartford with some research capacity in the development of an HIV prevention research and intervention program.
- CDC has told the organization that Hispanic drug users are at highest risk at that time.
- What research partners would you consider and why? How would you set up the partnership?

Involvement of partners in the research process

- Research partnerships should be collaborative.
- Research teams should include all necessary partners by substantive area (intersectoral) and discipline (interdisciplinary)
- Investigators and staff should reflect the ethnic, racial and other characteristics of the study population,
- The research team should develop clear and mutually agreed upon policies regarding joint ownership of data and dissemination of research results.
- The research partnership team should disseminate findings to all partners, including the community in which the study takes place.
- The research team should address and resolve issues of power and power differentials, and experiences of discrimination among members of the research team

Understanding the community

- What would researchers want to know about the community related to HIV?
- What would organization partners need to know about the community
- What are ways they each could find out about it
- How could they help each other to find out about community and community needs.

Understanding and Concern for the Research Community

- The study community should be clearly identified.
- Members of the study community should agree to the study and its importance.
- Members of the research team should demonstrate an interest in and commitment to working in and with the study community.
- Members of the study community and knowledgeable researchers should ensure that information and knowledge about the community is incorporated and applied in all phases of the research process (planning, implementation, evaluation, analysis and dissemination).
- The research team and members of the identified community should demonstrate a mutual understanding and respect for the culture(s) of the research partners and study community

Purpose of Research

- How would you as researcher or CBO leader convey the study and its importance?
- What would be important for you to know in order to do this effectively?

Relevance and benefit of the research

- All partners should agree on the relevance and benefits of the research to science and community(s).

- The research topic should be relevant and of benefit to the community(s)

- The research should identify and address health disparities experienced by the community(s)

- Researchers and community members should share the process of ensuring that the research results have an impact on both science and community welfare.

Effective communication

▸ In the proposed project, the team leadership consists of two white researchers and an African American coordinator. The project cuts across multiple communities in Hartford. Is there something wrong with this picture? What would improve it?
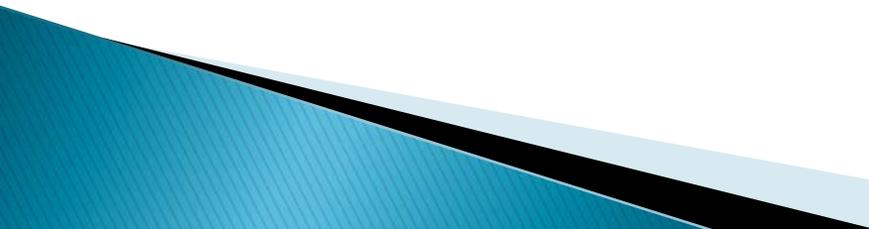
Effective communication among partners

- Communication should be bi-directional; all partners should have an equitable voice in the research process.

- The research team should establish policies that foster open and effective communication and create a structure that supports conflict resolution.

Ethics

- In the project described, how should the burden and the benefits be distributed?
- What might be the risks for the field staff in a KAB study in the early years of the HIV epidemic?

The ethical conduct of research

- All members of the research team must be trained and certified in the protection of human subjects.

- The Institutional Review Board (IRB) conducting the review of the research should include people familiar with community-based research on the review board..

- Pay attention to risks, benefits and costs of the study for the study staff, participants and the community.

- Develop joint protocols and resources to refer participants especially around sensitive topics. The referral resources should be relevant.

Recruitment

- In this example, if a faculty member wanted to have a CBO recruit for them and their study, under what conditions might that be acceptable?
- Not acceptable?

Recruitment process

Establish a relationship with community organization and members beforehand.

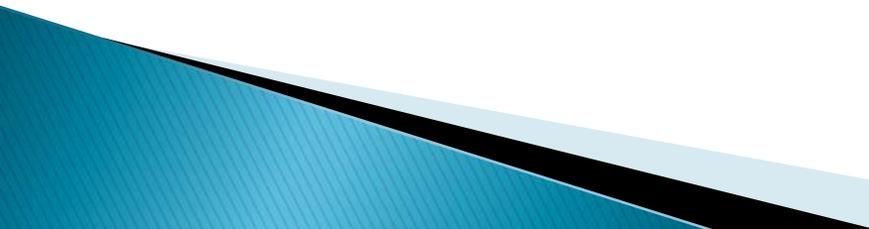Do not see CBOs simply a tool for recruitment;

Researchers should take time to build trust and explain details about study.

Researchers should work with CBOs to make the connection between the study with community concerns.

Researchers and partnership teams should discuss with CBOs and their clients the real and perceived risks and benefits of the research.

CBOs should have a clear understanding of the researcher's needs and expectations, and should clearly identify their capacities and limitations

Recruitment

- Create opportunities to inform the community about the research and its utility;

- Provide credible reasons why community residents should participate;

- Make an effort to accommodate people's personal schedules to facilitate their participation in the research process;

- Develop strategies to share results of the research with the study community, including study participants.

- Researchers and CBOs should be open to additional research possiblities.

Capacity building

- What could the organizations gain from this experience
- What could the faculty member or other researcher gain from this experience
- Who should the results be shared with?

Capacity-building, resource sharing and sustainability

- The research partnership should promote co-learning and capacity building among all partners, including, but not limited to:

  ◦ Funding; Grant writing; Improving organizational credibility; Increasing knowledge of research ethics and individuals' rights as participants in research;

- The research partners should negotiate agreements on resource sharing across the partnership throughout and re-negotiate on an as needed basis over time.

- Research partners should work to:

  ◦ Sustain and advocate for community-university research relationships;

  ◦ Support and work toward funding for a longer term program of research at the organizational and broader community levels.