Community Partners/Working with HIV/AIDS Community Advisory Boards Worldwide

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Abstract

Community Partners is coordinated through the Office of HIV/AIDS Work Coordination (HANC) based in Seattle, Washington at the Fred Hutchinson Cancer Research Center. HANC works with the U.S. National Institutes of Health (NIH) HIV/AIDS Clinical Trials Networks with the intent of creating a more integrated, collaborative and flexible research structure.

Community Partners (CP) seeks to promote effective representation of the many communities within which the NIH HIV/AIDS Clinical Trials Networks conduct research. CP helps to facilitate and enhance community representation and participation at all levels. The booth will promote CP activities and training resources developed, specifically designed to train and support the NIH HIV/AIDS Clinical Trials Networks and site CABs and research staff globally.

Community Resources

- Recommendations for Community Involvement in NIAD Clinical Trials Networks to maximize the scope, effectiveness, and benefits of community engagement in clinical research.

Community Partners Locations

NIH HIV/AIDS Clinical Trials Networks

CP Cross-Network Activities & Mission

- Community engagement
- Scientific agendas
- Ethical conduct of clinical trials
- Community education
- Communication/information dissemination
- Community participation
- CAB support

Community Partners Accomplishments

- Participated on a working group to support revision process for the UNAIDS/HANC Good Participatory Practice (GPP) Guidelines for biomedical HIV prevention trials.
- Collaboration with the TB Alliance on clinical and community engagement program strategies and initiatives to provide input on clinical and community engagement strategies, and assist in how to prioritize and appropriately engage various constituencies in a dialogue related to TB drug development programs, clinical programs, scientific and ethical considerations in the fast-changing landscape where TB and HIV research is being conducted (2010–ongoing).
- Developed the CP CAB website and in-country site staff surveys to assess community participation at the site level (2010–2011). Provided information/input to DAIDS and Network Leadership to develop recommendations pertaining to site-level CAB funding, based on survey findings and community experiences.
- Conducted annual community research priorities and presented agenda at HANC Leadership at the 2011 12P Meeting.
- Participated with the CP's SDP site-level funding PIRQ formed a working group and submitted a manuscript based on the results of the CP 2010 survey. The manuscript was published in August 2012 in Progress in Community Health Partnership: Research; Education, & Action.
- Provided cross-network input to DAIDS to support the development of ethical guidelines and considerations into trial design and conduct. Provided talks and feedback on the DAIDS’ Informational Fact Sheet for Stored Specimens (2013-2018).
- Developed a Basic Science Library Module for community education and training.
- Formed a Strategic Planning Work Group in October 2010 to revise CP's values and mission, develop a series of goals which will describe and define the work of CP over the next three years and identify key strategies to reach the identified goals and address key issues.

Community Partners Strategic Plan:

Goal 1: Facilitate and enhance community representation and input at all levels in HIV/AIDS and related clinical research within the networks.

Goal 2: Increase knowledge and awareness of CP: CP tools, and Network activities.

Goal 3: Support efficiency and effectiveness of local and network community advisory boards, and engagement of stakeholders.

Goal 4: Address challenges to community engagement in clinical research.

Community Partners & The Legacy Project

CP seeks collaborative efforts with other groups and organizations to invite, promote and support representation of communities within which the NIH HIV/AIDS Clinical Research training and research activities. CP has members serving on the UNAIDS-funded Legacy Project.

Mission Statement: The Legacy Project's mission is to build trust and collaboration among researchers, research institutions and historically underrepresented communities most impacted by the domestic HIV epidemic; to enhance cultural competence; and to initiate scientific investigation to increase viral research participation.

Programmatic Focus Areas:

- Research: Funding, Coordination, and Evaluation
- Capacity Building
- Engagement & Collaboration
- Technical Assistance
- Training