



A novel and focused approach to Community Advisory Board (CAB) development and maintenance builds community members' capacity to educate consumers about HIV clinical research, resources, and health maintenance.

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Introduction

Community Research Initiative of New England (CRI) is the only independent, non-profit, community-based organization in New England dedicated to HIV clinical research, treatment education, and financial assistance for approved drug treatments and health insurance coverage.

CRI's CAB is comprised of 17 racially and ethnically diverse and dedicated members who meet monthly. Membership is comprised of research participants, community members, and advocates. Maintenance of an active CAB with longstanding members allows for structured capacity building and knowledge building of this group's community advocacy skills.

CAB Mission and Goals

MISSION

The CAB will serve as the community liaison of CRI and will advise, assist, recommend and review the agency's research and educational activities.

GOALS

- To be an open forum for community concerns and needs and how CRI can address such through its research and educational activities.
- To work with staff to review new study protocols and provide feedback on research efforts.
- To ensure that CRI works with all populations and assists in improving their access to and enrollment in clinical studies and available treatments.
- To maximize the dissemination of culturally and linguistically relative information about treatment options to consumers and providers in all communities, in order to help them make more informed decisions about their care.
- To develop, foster, and provide a place for on-going dialogue with all communities affected by HIV.



"I talk to people about living with HIV and help people make informed decisions about joining clinical HIV trials and getting treatment."

Jack Augustus, CRI's Community Advisory Board



"I represent people living with HIV. I tell the community that you don't have to be afraid of clinical trials because they will make your life better."

Iris Rivera, CRI's Community Advisory Board



Above: members of the CRI CAB



Right: Member Lester Payne participates in a broad range of awareness campaigns in the community



Above: CAB Members Ben and Jack at the H2B Charity Ride, representing Positive Peddlers and the CRI CAB

Agency Commitment

CRI's commitment to the CAB includes identifying and supporting one dedicated agency staff member to facilitate the group. The CAB Coordinator organizes meetings, provides technical and administrative support, and serves as a link between the agency and the CAB.

CRI's Crucial Components of CAB Development and Maintenance

- Dedicated and consistent agency staff time
- Member-derived mission and goals statement
- Self-governing bylaws with frequent review
- Consistent access to information and investigators
- Membership incentives (i.e. small stipend, dinner at meetings)
- Ongoing training and education
- Access to participate in local events and attend conferences
- Encouragement and reward of long-term membership
- Focused appreciation – membership recognition
- Personal touch – handwritten notes, consistent, respectful interaction
- Mentorship program for new members
- Annual assessment by CAB and agency to prioritize projects and educational programs by community need

Member Activities in the Community

Members build capacity in their respective communities through the following activities:

- Distribution of brochures and literature
- Formal and informal speaking engagements
- Distribution of pill-charts and health literature
- Community referral for open and enrolling studies
- Community referral for drug assistance program access
- Identification of community service providers with information needs
- Providing information on services and research to local ASOs, clinics, and peers
- Informal peer education
- Local awareness campaigns

Implications for Practice

Focused development of a satisfied and integrated CAB as an active educational recruitment and outreach body aids to inform the community about HIV clinical trials, HIV health literacy, and improves access to critical programming and research. Through strategizing ways to develop and maintain a successful community advisory board, an agency can develop partnerships with community members, effectively building their capacity as advocates for research, providers of health education, and an avenue of access to resources in their communities.