



# BEAT-HIV

## DELANEY COLLABORATORY

### **Community Advisory Board Fact Sheet**

Members of the BEAT-HIV Delaney Collaboratory to Cure HIV-1 Infection by Combination Immunotherapy, BEAT-HIV Collaboratory Community Advisory Board (CAB) serve to build and foster partnerships between researchers and local study communities impacted by HIV/AIDS. An active CAB with a committed membership is an integral part of the effort to combat HIV/AIDS. CABs can also help strengthen local capacity to support critical research needs involving an HIV cure.

The success of BEAT-HIV's research agenda depends upon active participation by the communities involved in the studies. The meaningful inclusion of community members at all levels of the research process helps build trust and mutual understanding of HIV cure science and research while ensuring that participants' values and cultural differences are respected.

#### **Function of the BEAT-HIV CAB**

Typically, a clinical research site (CRS) obtains community input into the research process through community advisory boards, although a CAB may refer to this structure by any locally chosen name or establish an alternative structure. Community representatives provide input to protocol teams, particularly in adapting sample consent forms for local use and in developing other study materials to be shared with community members. CABs provide advice on scientific, ethical, and operational issues regarding study design, recruitment strategies, and protection of study volunteers. Each CAB develops its own mission statement and operating guidelines.

CAB members may be of diverse backgrounds (e.g., race, color, religion, sex, gender, sexual orientation, national origin, age, ability, and/or socio-economic status, etc.). They may contribute professional or personal experience (e.g., people living with HIV/AIDS, current and/or former study volunteers, and/or representatives from community-based/nongovernmental organizations).

The BEAT-HIV CAB is responsible for providing critical feedback on the impact of BEAT-HIV studies on local communities. Members serve as a voice for the community and study participants. CABs bring specific, unique expertise to the research process, by participating in the processes that define the BEAT-HIV agenda while informing researchers of local issues or concerns that can affect the conduct and successful implementation of the BEAT-HIV scientific agenda. Face-to-face meetings facilitated by BEAT-HIV staff provide opportunities for CAB members to share their community expertise, insights, experiences, and to gain new skills. Compensation for CAB members should be offered to offset legitimate costs of participation in the advisory process, such as reimbursement for transportation, meals and other reimbursements that are deemed appropriate at the local level but that do not include payment.

The BEAT-HIV is unique in that it works in partnership with scientists and community-based organizations who provide services to people with HIV, to form a Community Engagement Group (CEG); see image below. Members of the CEG are available to participate in CAB meetings to support continued community engagement. They are also encouraged to support representative CAB members' participation in BEAT-HIV meetings and trainings.



## BEAT-HIV CAB Member Recruitment

BEAT-HIV CAB members are recruited from the communities mentioned previously and through recommendations from leaders in the community, other CAB members, study participants, and BEAT-HIV staff. Recruitment should be viewed as ongoing, wherein new members are added over time as attrition occurs. Site community education staff and/or CAB coordinators will provide new CAB members with an orientation and background materials prior to their first meeting.

To ensure CAB autonomy and to reduce the potential for conflict of interest, full, voting members of the BEAT-HIV CAB are volunteers from the community and are not paid staff members of BEAT-HIV or its affiliates. To serve on a CAB, members agree to certain terms of membership, generally having to do with roles, responsibilities, and meeting attendance. CAB members are expected to participate meaningfully so that issues requiring community dialogue can receive appropriate attention.

## Responsibilities of BEAT-HIV CAB Members

- Attend local CAB meetings and provide feedback on issues under discussion.
- Voice concerns from the communities and study participants.
- Demonstrate commitment to developing an understanding on issues where they may have little expertise.
- Participate on BEAT-HIV scientific committees and community working group as appropriate.
- Assist in the development and implementation of community education activities (health fairs, community forums, community sensitization/mobilization activities, etc.) and materials.
- Advise the site research team and BEAT-HIV protocol team in the development of informed consent forms and other study related documents.

- Provide real-life experiences.
- Serve as a resource to community liaison officer/community educator and research team.
- Disseminate study information to local community.
- Recruit and orient new CAB members.

### **Additional Information and Contact Details**

If you would like to learn more about the BEAT-HIV CAB, please contact Amy M. Onorato at [onorato@penmedicine.upenn.edu](mailto:onorato@penmedicine.upenn.edu), or 215-746-7352 or visit us online at <https://beat-hiv.org>.