

Unit 10

Community Advisory Boards

Overview

In this unit trainees will learn about the role of a Community Advisory Board (CAB) for HIV vaccine trials at the site level, within the HVTN at a network level, and how site staff can best support them. Trainees will learn how CABs came to be, what CABs aim to do, and how CABs can help move the science of HIV vaccines forward.

Objectives

By the end of the unit trainees will be able to:

- Describe what a CAB is
- Describe the CAB's role and responsibilities
- Describe how to form a CAB
- State the site's responsibilities in providing support to CAB members

Materials

- *HVTN CAB Overview.ppt – 1 copy per trainee*
- *Flip chart paper and pens*

Approximate time 2 hours



Warm-up/Introduction (20 minutes)

Trainer notes

The goal of this exercise is to try to get the group to see a Community Advisory Board (CAB) as a group of people who advise the site about community concerns and additionally advise the community about the work of the site. The CAB plays the role of a bridge between the

scientists and the community to help increase community participation in the planning, development, implementation of the study and dissemination of study results. The HVTN uses the name “CAB” as the default term, but sites may call these groups by any name they choose such as Community Advisory Group (CAG), or Community Working Group (CWG).

Procedure

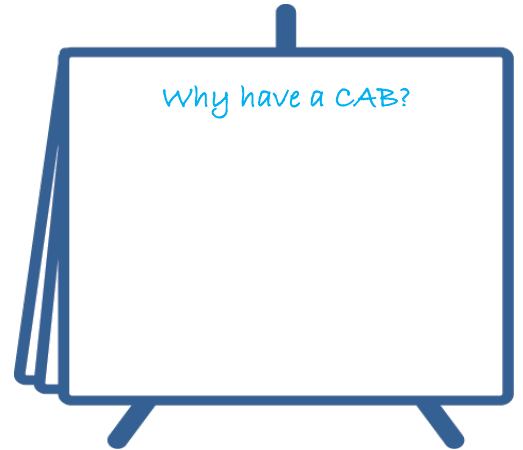
Step 1: Ask the group, “What is a Community Advisory Board (CAB)?” Go around the room and ask for an idea from each person.

Step 2: Write on a flipchart - *Why have a CAB?*

Step 3: Elicit responses from the group and write them down as they are given.

Use this list sample responses if the group gets stuck:

- Provide guidance to the site from a community perspective.
- Participate in the development and ensure the appropriateness of engagement materials.
- Ensure that the site is engaged in community issues.
- Provide advice on protocol development and the informed consent document and process.
- Act as an audience for staff to practice presentations and messages before speaking with the general public.
- Provide guidance on how to build relationships with targeted recruitment population.
- Assisting with community engagement events and activities



Step 4: Ask why they think it’s important that all vaccine trial sites have a CAB.

Step 5: Ask what information should be provided to CAB members and what things the CAB should be provided updates about.



Presentation of Information (20 minutes)

Trainer notes

This presentation highlights how CABs came to be, what CABs aim to do, and how CABs can help move the science forward.

Preparation

- *HVTN CAB Overview.ppt*

Procedure

Step 1: Present slides reading through the speaker's notes. Stop for questions as they come up.



Group work (60 minutes)

Trainer notes

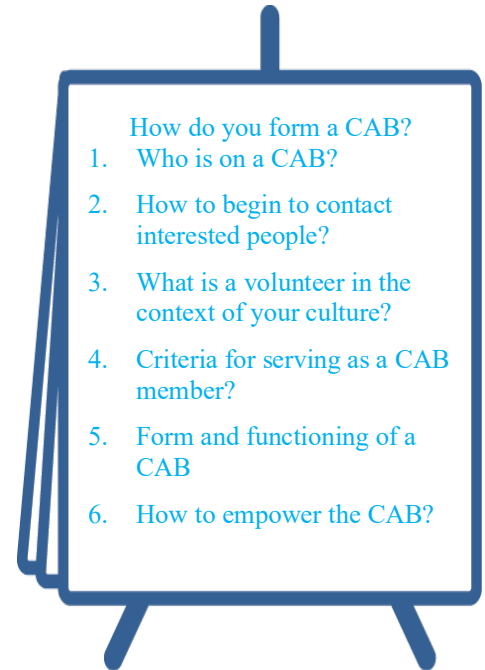
- If the site **does not** yet have a functioning CAB: Do Exercise 1, skip Exercise 2 and then continue with Exercise 3.
- If the site already **has** a functioning CAB, skip Exercise 1 and start with Exercises 2 then 3.

Procedure- Exercise 1

Step 1: On the flip chart sheet write: *How do you form a CAB?* Go around the room and ask for ideas from the trainees. Try to get the group to identify the questions that must be addressed, as written on the flipchart example.

Step 2: Once the trainees have identified the key issues of forming a CAB, tape this flipchart sheet on the wall. Now begin to develop each issue with specific information provided by the trainees.

Step 3: Write on a new flipchart sheet: *Who is on a CAB?* (refer to any earlier discussions you may have had about important audiences to target for community education)



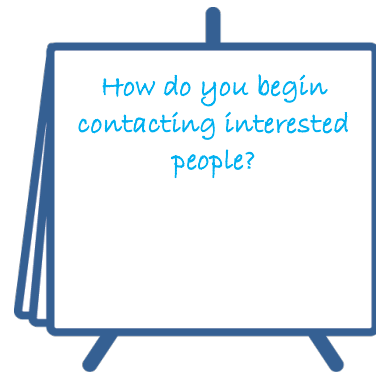


Step 4: Work with the trainees to name specific groups that fall under various audience categories. (Examples: NGOs/CBOs, Youth, Traditional Healers, etc.)

Remind the group that CAB members don't necessarily need to represent an organization or organized group. CAB members can also represent neighborhoods and occupational groups such as artists, teachers, taxi and truck drivers, tailors, etc. Remind the group that the ultimate goal is to create a CAB that represents "the community."

Step 5: Write on a new flipchart sheet: *How do you begin contacting interested people?*

Step 6: Elicit ideas from the trainees. Try to help them recognize the importance of the site's outreach team going out into the communities to talk about CABs, HIV vaccines and research with the goal of identifying interested individuals to invite to a larger informational CAB meeting.



Here are some suggested responses if the group gets stuck:

- Begin by recruiting those already interested in HIV/AIDS (AIDS service organizations, health care providers, non-governmental organizations, etc.)
- Consider various meeting locations to accommodate people's schedules
- Offer food, stipends, and swag to participants
- Solicit information through Medical Case Managers, Infectious Disease Healthcare Providers, and others who engage with potentially interested populations.
- Have information sessions every week/every other week/every month for open forum discussions by community groups regarding HIV/AIDS, HIV Vaccines, Research, etc.
- Go out to individual groups and give presentations
- Call key leaders of community groups and invite them to information sessions



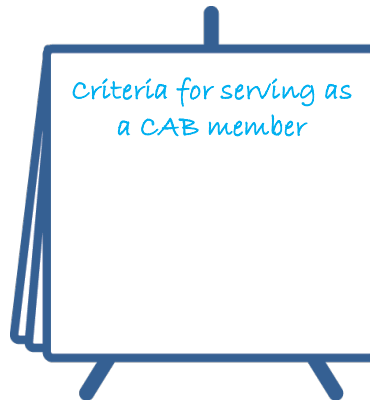
Step 7: Write on a new flipchart sheet: *What is a volunteer in the context of your culture?*

Step 8: Ask the trainees this question and write their thoughts on a flipchart sheet. Ask the group for reasons why people volunteer. It might be important to state that in many cultures people volunteer for reasons such as personal growth, career development, personal identity, building a sense of shared community and giving back to society, or altruism (wanting to help others).

Point out that as they begin to go out into the community and speak to potential CAB members, they can use these key ideas about why people volunteer to interest people in participating in the CAB.

Step 9: Write on a new flipchart *as a CAB member*.

Step 10: In addition to finding motivations to be on the CAB, it people that can meet certain the work that needs to be done. some criteria might be for participate and achieve the



sheet: *Criteria for serving*

people with the right is equally important to find criteria to be able to do Ask the trainees what people to successfully goals of a CAB.

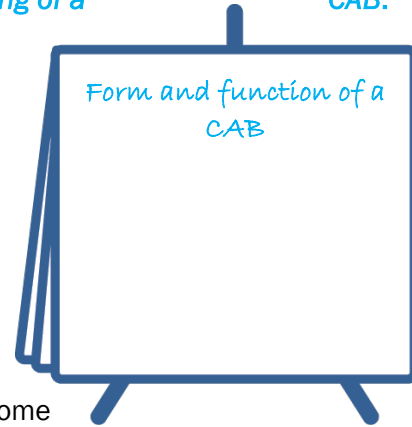
Sample criteria might include:

- Motivated
- Have time to commit to this endeavor
- Available to attend meetings
- Easily reachable by phone or email.
- Supports HIV/AIDS issues
- Ability and willingness to report back to their own community

Step 11: Write on a new flipchart sheet: *Form and functioning of a*

CAB.

Step 12: The trainees will begin to identify how the CAB will be formed and how it will function. The typical CAB structure that has been used successfully in multiple networks is described below: (Write these bullet points on the flipchart paper, and explain the context by which each point was identified).



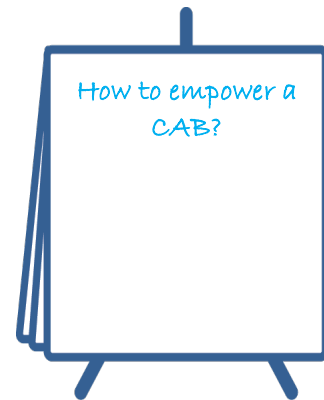
- **No more than 20 members.** To be able to manage a successful working group, the CAB should not be too large. If the group is concerned about excluding some portion of the community by limiting the CAB size, a quarterly community update program could be organized to present information about what the site is doing and the work of the CAB to date or the CAB could organize into various subcommittees to work on different aspects of CAB involvement. This larger group forum could be led jointly by the CAB and the CER.
- **Meet at least once a month.** CABs should meet at least once a month to ensure a sense of continuity and consistency. The group may decide to meet more frequently if they choose.
- **Meet for at least one hour:** One hour is the minimum time, however with the amount of training and work to be done CABs may initially want to hold the meetings for longer - at least 2 hours.
- **Plan an educational component for each CAB meeting.** This is especially important within the first year of the CAB's existence. People can only advise on a topic when they have accurate information and are knowledgeable.
- **Plan an educational CAB retreat.** If the CAB is unable to meet for more than one hour a month or would like to spend an extended period of time training on a particular topic, a retreat can be held. This would involve planning a half-day or an entire day for the CAB to come together to be trained and work on the topics they decide are important (preferably on a weekend when most people are off work).
- **Co-chairs appointed or elected by the group.** Leaders typically serve for a period of at least one year. This is important for maintaining the structure and continuity of the group.
- **A site staff member is designated to support the CAB.** Usually the Community Educator or Community Liaison Officer is responsible for supporting the needs of the group. This could include scheduling and attending meetings, providing snacks, taking minutes, preparing copies of materials, and providing any other service to facilitate the CAB meeting.

- **Establish Operating Guidelines.** The CAB should have a list of policies, procedures, and role descriptions to ensure that decorum is maintained and that the group is run consistently. This helps to protect the integrity of the CAB, ensures that the group can work effectively, and that all members are treated fairly.
- **Elect a Global CAB (GCAB) representative.** This person will participate on the bi-monthly Network-wide GCAB calls for a term of at least one year. To ensure continuity it is important for one person to be able to sit in on calls and report back to the local CAB. This will allow the local representative to follow ongoing discussions and feel more comfortable contributing to the GCAB discussions. A back-up or alternate representative can also be selected to ensure that the site will be represented on each monthly call.

Step 13: Remind the group that these are general guidelines. It will be up to each individual CAB to determine how they will function.

Step 14: Write on a new flipchart sheet: *How to empower the CAB?*

Step 15: Elicit ideas from the trainees and write them on the flipchart sheet. Try to get the group to identify education as one of the ways to empower the CAB. The main point is that an educated CAB is an empowered CAB.



Procedure – Exercise 2

(If the site does not yet have a CAB, skip this exercise)

Step 1: Write on a flip-chart sheet: *What has the CAB achieved?*

Step 2: Elicit responses from the trainees and write them down as they are given.

Here are some responses if the group gets stuck:

- Reviewed an informed consent document from a new protocol prior to local IRB submission.
- Helped develop local engagement materials.
- Gave feedback on places to recruit specific populations.

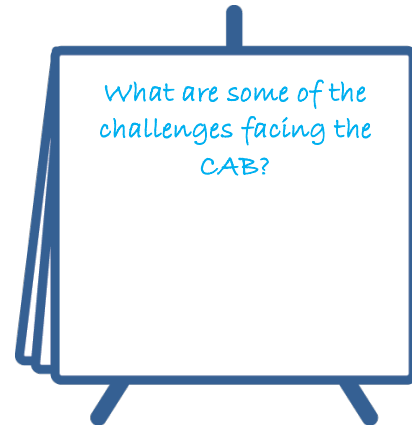


Step 3: Write down on a flip-chart sheet the question: *What are some of the challenges facing the CAB?*

Step 4: Elicit responses from the trainees and write them down as they are given.

Here are some responses if the group gets stuck:

- Inability to recruit new members to ensure a diverse CAB
- Limited communication among CAB members
- Retention of trained and involved CAB members

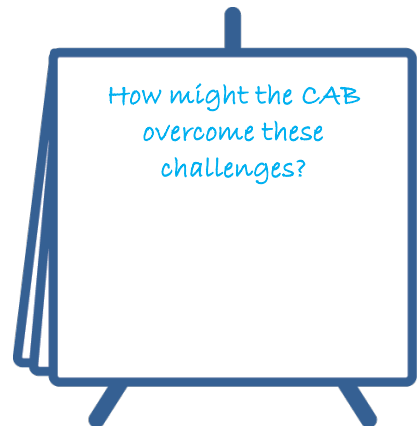


Step 5: Write down on a flipchart sheet the question: *How might the CAB overcome these challenges?*

Step 6: Elicit responses from the trainees and write them down as they are given. Brainstorm with the group other ways the CAB may be able to overcome the identified challenges.

Examples of challenges and possible solutions

- Inability to recruit new members or a diverse CAB. (The CAB could move its meeting location or time to try and accommodate new people.)
- Limited communication between CAB members. (Develop an e-mail alias to increase correspondence.)
- Retention of trained and involved CAB members (Provide CAB members with an anonymous survey to find out their reasons for joining and what would make them want to quit; organize a CAB appreciation event).



Procedure – Exercise 3

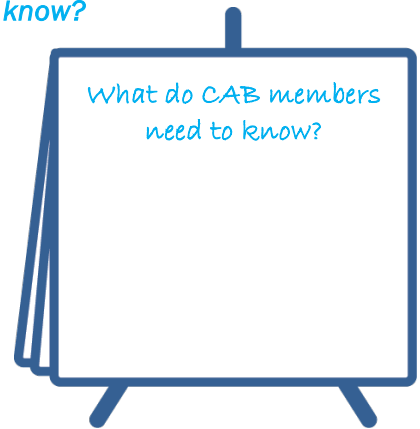
Step 1: Write on a flip-chart: *What do CAB members need to know?*

Step 2: Explain to the group that it will be important for the CAB to work with the site staff to develop a curriculum to help the CAB get up to speed on the necessary information.

Elicit responses from the trainees and write them down as they are given.

Here are some ideas if the group gets stuck:

- The science behind HIV and how infection occurs.
- The science behind vaccines.
- How to read a protocol and informed consent document.
- Ethical considerations in HIV vaccine clinical trials



Step 3: Ask the group: *How do we keep CAB members informed?* (About the important subjects just listed above)

Responses may include:

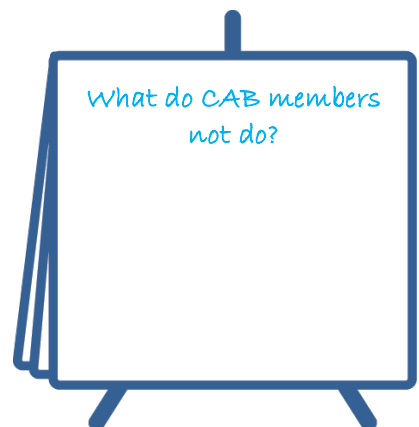
- Developing a training calendar
- Inviting scientists to give presentations or join the CAB for a discussion
- Participating in HVTN Full Group Meetings
- Conference calls
- CAB Retreats
- Site Community Newsletter
- Emails
- Google group for sharing documents



Step 4: Ask the group to discuss: *What do CAB members NOT do?*

These could include things such as:

- Follow participants in the informed consent process



- Actively recruit participants into trials
- Provide for the ultimate well-being of the participants

Step 5: It is key that CAB members know they are not ultimately “responsible” for the well-being of the volunteers. They give **advice** to the site in order to improve the volunteers’ understanding of a study, but ultimately the legal responsibility falls into the hands of the site’s principal investigator and IRB/ethics committees.



Wrap-up Activities (10 minutes)

Procedure

Step 1: Ask the group what they believe is the importance of having a CAB. If the first couple of answers do not quite match what was taught in this section, continue to move around the room until someone responds with a correct answer.

Step 2: Reinforce the answer by repeating it, expanding on the “why have a CAB?” sheet and ending with the CAB as a bridge between the site and the community.

Additional resources

- CAB Board Building Table.doc
- HVTN Manual of Operations CAB Description
- CAB training resources from the HIV/AIDS Network Coordination center (HANC): <https://www.hanc.info/resources/sops-guidelines-resources/community.html#community-engagement>
- IAVI: Guidance Tool for Community Advisory Boards
- UNAIDS/AVAC: Good Participatory Practice Guidelines
- SAAVI: Guidelines for Community Advisory Groups

The HIV Vaccine Trials Network is supported through a cooperative agreement with the National Institute of Allergy and Infectious Diseases