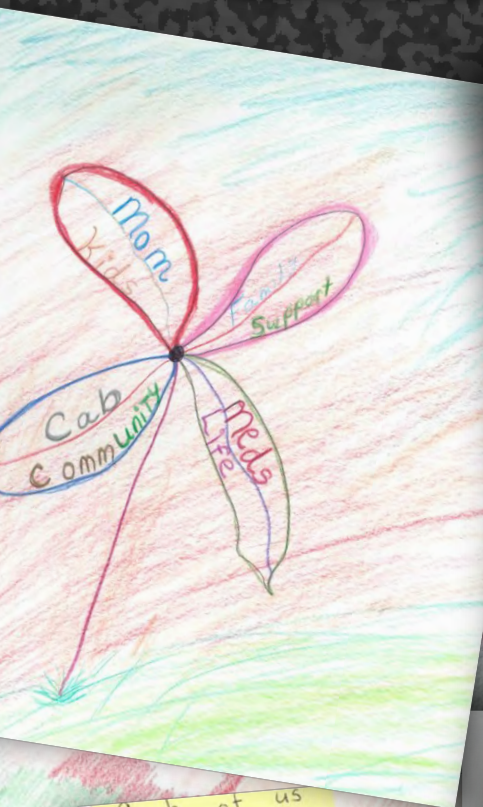


# CAB HANDBOOK

Produced by:  
Pediatric HIV/AIDS Cohort Study (PHACS)  
Health Education and Communication  
Community Advisory Board (CAB)  
Subcommittee



Each of us  
are a different  
color, but look  
how pretty they  
come together.

Community  
all connected - Even if we are  
different



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# PHACS CAB

## PHACS Community Advisory Board Overview



All clinical sites participating in the Pediatric HIV/AIDS Cohort Study (PHACS) are expected to have a Community Advisory Board (CAB). The purpose of the CAB is to seek input from community representatives in order to reflect the interests of participants and caregivers in PHACS. The PHACS CAB is also a forum for local CAB members to share resources and support.

The mission of the PHACS CAB is to serve as a connection between researchers and community members in order to improve and optimize clinical research studies for children/families who are participants, and who are most affected by the research.

CAB membership reflects the diverse local community. Each CAB should include people who have participated in the past or are currently are enrolled in PHACS or a similar research study. CAB members may also include:

- **Direct stakeholders:** Women with HIV, pregnant women with HIV, and parents/caregivers of HIV-infected and affected babies, children, and young adults who are enrolled in PHACS or similar research studies.

# PHACS CAB

- **Indirect Stakeholders:** Community members affected by HIV, including professionals (i.e., social workers, HIV program specialists, etc.).
- People who were or are currently enrolled in PHACS or a similar research study as a participant.
- Volunteer helpers, peer trainers, CAB liaisons, and counselors at the clinical site.

CAB members should not be responsible for recruiting new participants for research studies. However, CAB members may inform potential participants of how to get in touch with the study site.

## CAB Structure

Each PHACS local site CAB selects one representative to serve on the broader PHACS CAB. By majority vote, the PHACS CAB elects a Chair and a Vice Chair, each to serve a term of two years. The CAB Chair also serves as a non-voting member of the PHACS Executive Committee. As part of PHACS Leadership, the CAB Chair and Vice Chair are invited to attend annual PHACS Spring Leadership Retreats. Several PHACS CAB members are also members of the Health Education and Communication Committee.

## More Information

The PHACS CAB is a study-wide CAB. More information about the PHACS CAB can be found at: <http://phacsstudy.org/Education-Hub/Adult-Community-Advisory-Board>.

# SETTING UP A CAB

## Module 1

### Recruiting Site CAB Members—Where to Recruit

Current CAB members, Study Coordinators, and CAB Liaisons may recruit new site CAB members at any location or event where they might find eligible site CAB members ([see page 5-6](#)). Most PHACS site staff and CAB members recruit directly at the study site. This may include hanging posters and flyers in the clinic.

Some study nurses or social workers recruit parents/caregivers during study visits. Others recruit CAB members from other CABs/community organizations at the study site. Some sites encourage site CAB members to recruit their own family members. By recruiting at the study site, many sites have been able to create a very supportive environment for participants and people living with or affected by HIV/AIDS.

Feel free to get creative when thinking about where to recruit site CAB members! Some PHACS site staff and CAB members recruit members in schools, places of worship, and even public health events.

Many site CAB members found recruitment assistance from site staff very helpful.



# SETTING UP A CAB

## Module 1

Social workers and study coordinators have been successful recruiting CAB members at study visits. Some sites have a CAB Liaison on the staff. The CAB Liaison may also play a crucial role in recruitment. At some sites, CAB Liaisons call all CAB members to give them details and logistics about future CAB meetings. Some CAB Liaisons and staff members set up recruitment information booths in the clinic cafeteria.

“Being a part of the CAB [helps me] to understand the needs of the parents and goings on in the community in which they live.”

-CAB Liaison

### CAB Involvement in Recruitment

Current CAB members are involved in recruitment at many PHACS sites. Some CAB members invite other parents/caregivers that they know from other community groups or clinic visits. Although CAB member involvement in recruitment can be very helpful, be mindful that some CAB members may not feel comfortable recruiting CAB members from the community outside the clinic due to stigma, confidentiality, and/or other important reasons. Encourage CAB members to recruit new members from:

- Similar community groups;
- Their family and friends;
- Clinics; and/or
- Local public health events.

Ask CAB members and site staff about CAB member involvement in recruitment. It may be helpful to think together about how current CAB members became involved in the CAB.



# SETTING UP A CAB

## Module 1

### Barriers to Recruitment

Barriers to recruitment may include:

- Language
- Stigma
- Attitudes
- HIV disclosure
- Average age
- Conflicting schedules
- Availability of childcare
- Transportation

Many sites have found ways to overcome some of these barriers.

#### *Language*

In an effort to overcome language barriers, some sites have a site staff member interpret the meeting into Spanish. The interpreter participates in the meeting and interprets for Spanish-speaking CAB members at the same time.

#### *Stigma, Attitudes, and HIV Disclosure*

Participants in HIV studies may feel vulnerable to stigma, rejection and isolation due to their HIV diagnoses. Some people may not be comfortable disclosing their HIV statuses to others. They may worry about people revealing their diagnoses outside of CAB meetings.

Site CABs can help make CAB members feel safer by making CAB meetings a safe and confidential place. In one case, a Client Advocate & Retention Specialist runs the CAB meetings. This staff member also works with members to help overcome stigma. ([See page 34 for more information on confidentiality](#)).

# SETTING UP A CAB

## Module 1

### *Average Age*

Most PHACS Site CABs do not have many adolescent/young adult members. Young people may feel out of place being around mostly adults. Reach out to this population and try to include them in recruitment. There may be alternative ways to involve young people in site community efforts. Some sites set up summer camps and after-school groups for young adults.

### *Conflicting Schedules*

It can be tough to schedule CAB meetings during a time that works for everyone. Some site CABs find it helpful to schedule meetings in the evening. Evening meetings allow for school-aged teens and working adults to come to the meetings. One site found it helpful to schedule meetings at 6:00 PM. This is right after work for many people. It allows members to come to the meeting on their way home from work. They eat dinner at the meeting and make it home before it gets too late. Other sites find it helpful to schedule meetings during lunchtime.

Consider providing teleconferencing options. This would allow CAB members to attend the meeting over the phone or internet. Some sites use site conference call lines or Skype.

In conclusion, it may always be challenging to schedule meetings at a time that works for all. Talk to site CAB members. Come up with a time that works for the most people, and try it out. Many sites have had to try out different times and wait and see what really works.



# SETTING UP A CAB

## Module 1

### *Availability of Childcare*

CAB members may have a hard time coming to CAB meetings if they do not have childcare. Site staff or even other CAB members may be willing to babysit during CAB meeting. Some sites have a child-friendly area with books, movies, and toys. One site gives children an art project to work on during the CAB meetings.

### *Transportation*

CAB members may not live near the meeting location. Some CABs encourage members to carpool to meetings. If funds are available, sites may offer transportation "perks" to CAB members like bus passes, free parking, or gas money. These can help make it less costly for CAB members to come to meetings ([see page 17 for more information about transportation incentives](#)).

### **Mission Statement**

One of the first steps in setting up a CAB may include making a mission statement. Mission statements are often created by members of the CAB and CAB liaisons. A mission statement can help define the site CAB's purpose. A mission statement answers the question, "Why do we exist?" As a group, consider your goals for the CAB. Think about what the group would like to accomplish. Some sites come up with yearly goals. They make sure to think about their mission statement as they come up with goals for the next year. Goals often have to do with what the CAB members want to do or learn.


Think about the PHACS CAB Mission Statement ([see page 6](#)). Try to come up with a statement that supports the PHACS CAB Mission Statement. Make sure it also represents the site CAB's own point of view.

# SETTING UP A CAB

## Module 1

### Retention

Site CABs may have some trouble keeping members involved. Many site CABs have come up with new and exciting ways to retain their members.



How do we keep our CAB members?

#### *Keep in Touch*

CAB members who keep in touch, stay together! CAB members or Liaisons can volunteer to call CAB members with meeting reminders. Some sites send meeting flyers to CAB members by mail or email. Many CABs use a buddy system. Each CAB member has a buddy and is in charge of helping make sure they know about the scheduled meetings. Site staff members may remind CAB members about meetings during clinic visits.

#### *Get Involved*

One of the ways to get CAB members to stay in the CAB is to help them get involved with CAB responsibilities. The CAB may choose a representative to take part in study-wide conference calls like the PHACS CAB monthly conference call. PHACS and other similar studies may invite CAB members to attend yearly in-person meetings or retreats. There may even be opportunities for CAB members to attend professional conferences.

Many site CABs come up with roles and responsibilities for site CAB Leadership. Consider asking the CAB about CAB Leadership positions. Vote for CAB Leadership members, or take volunteers. This is a way to get CAB members more involved, and spread the CAB workload.

# SETTING UP A CAB

## Module 1

### *Show Appreciation*

The CAB is a vital piece of the clinical research process. CAB members give very important feedback about the study to researchers. This feedback can be used to make the study better for study participants and researchers. Many sites have retained their CAB members by showing appreciation for the CAB's hard work. In addition to helping with the CAB, site staff members at sites with active site CABs make personal connections CAB members. Some sites celebrate CAB member birthdays, holidays, and CAB accomplishments!

### *Incentivize*

One of the most obvious ways to keep CAB members involved is to offer "perks" or incentives. Keep in mind that perks are not just about money. Perks can include learning opportunities, professional workshops, or resume building. ([See page 17 for more information on incentives](#)).



### **Funding**

Sites may or may not have funds available for their site CABs. Different groups may be responsible for funding. The research study may fund site CABs, but funding can also come from donations from outside organizations. One PHACS site CAB receives some funding from the local police department. Be mindful of state and institutional rules and regulations about funding. Talk to the site Principal Investigator about funding specifics.

# SETTING UP A CAB

## Module 1

Sites may use CAB funds to support CAB activities including (but not limited to):

- Food/Drinks at CAB meetings;
- Materials for CAB meetings such as binders, paper, handouts, pens, etc.;
- Classes and Workshops;
- Resources;
- Raffle prizes;
- Incentives;
- Childcare and childcare materials; and/or
- Transportation reimbursement.

Keep in mind that some materials for CAB activities may be donated. Local businesses may be willing to donate food or services. One site has received food donations from local businesses for their holiday party. Local volunteers came to help with the party and take pictures with Santa. Reach out to other community groups connected with the site. They may have a list of local businesses that actively participate in community service and/or give out donations.

### **Fundraising**

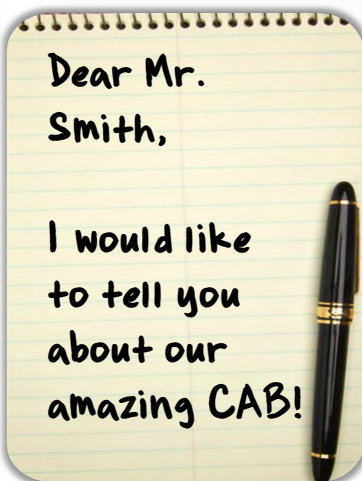
Although many sites find their own funding to be enough, some sites feel the need to do fundraising activities. Materials for CAB meetings may often be provided by the site. However, some sites have looked for additional support through fundraising to help pay for extra activities. These additional activities such as parties, raffles, and other fun activities may help keep CAB members involved. Although these kinds of activities are not typically included in budgets for research studies, they may help keep CAB members involved and enthusiastic.

# SETTING UP A CAB

## Module 1

There are many ways to fundraise! Many site CAB fundraisers have to do with using current CAB member skills and talents. If there are creative cooks in the CAB, try holding a bake sale. If there are artistic members of the CAB, try holding an art auction or festival. Take donations for CAB member art. One site CAB sold hand-made scarves and ear warmers to hospital staff. There are also often fundraising opportunities during the holidays. Set up a wrapping table at an approved location. CAB members could wrap gifts and accept donations. Accept donations for hand-made greeting or holiday cards. Consider other ways your CAB can utilize your CAB members' hidden talents!

Below are a few ways site CABs have raised money:



### *Letters to Local Business*

One site CAB sent letters to medical providers and local businesses. In the letters, they explained the purpose of their site CAB. They requested support for funding. This CAB used the funds to purchase gifts for their annual holiday party.

Be mindful that some sites may have regulations about sending letters to local businesses. Check with the site Principal Investigator to find out if approval is needed.

### *Ribbons*

One site CAB made support ribbons out of construction paper. They posted the ribbons in the clinic. People donated \$1 to write their name and/or a message on the ribbon. This CAB used the funds for site CAB meeting materials.



# SETTING UP A CAB

## Module 1

### *Bake Sales*

One site CAB held a bake sale around Thanksgiving. CAB members either made or brought baked goods to sell. They set up the bake sale table at the front entrance of the hospital. The CAB raised over \$600 for their annual holiday party. Consider asking CAB and site staff members to help bake.

**Important Tip:**  
Hold the bake sale on a pay day!

In some cases, fundraising can be used to support outside needs in the greater community. This includes emergency aid, camps for HIV-affected children, and housing support. Some site CABs fundraise for other organizations.

Site CABs have raised money to participate in annual AIDS Walks together. These kinds of fundraising efforts do not directly fund site CABs, but they help the CAB participate in outside activities and bond together.

Be sure to check with site staff for approval before organizing any fundraising activities. This is especially important because each site may have different rules and regulations regarding permitted fundraisers. If you are unsure of your site's policy, it may help to brainstorm a few ideas with the site CAB first. Then present the ideas to site staff.





# SETTING UP A CAB

## Module 1

### Incentives

Depending on the funds and resources available at the site, site CABs may offer incentives or “perks” to their CAB members. Remember, many incentives do not require money! Incentives may include (but are not limited to):

- Food/Drink
- Transportation
- Prizes
- Money and gift cards
- Access to educational resources
- Internet access/telephone access
- Networking with site staff and other CAB members
- Guest speakers
- Parties
- Leadership and professional opportunities
- Workshops
- Emotional support

#### *Food and Drink*

Depending on the time of the CAB meeting, site CABs might want to serve food and/or drinks during site CAB meetings. Some CABs provide full meals. Other CABs provide snacks. This can be an incentive to get CAB members to want to come to meetings. It can also help CAB members stay in the CAB. For example, CAB members may not want to come to meetings right after work because they are hungry. In this case, it may be helpful to provide dinner during or before/after the meeting.

Try to plan food/drink options based on the time of the meeting. One site CAB held meetings at 6:00 PM. This time was convenient because it was right after work.

# SETTING UP A CAB

## Module 1



At some point, this site stopped providing food and drink during the meeting, and instead the site gave CAB members gift cards for local restaurants. This was an incentive for some CAB members. However, other CAB members didn't have time to go to the meeting and then get dinner after the meeting using the gift cards. The site CAB noticed that because of this change, some CAB members stopped coming to meetings. Talk to site CAB members. If options are available, ask for their preference (gift cards or food during meetings).

### *Transportation*

One of the barriers to retention is transportation. It may be financially or physically difficult for CAB members to get to CAB meetings. Therefore, some sites offer transportation options. Options for transportation incentives include:

- Free parking/parking vouchers;
- Mileage reimbursement (i.e., total miles traveled to and from the meeting X \$0.565 per mile);
- Prepaid subway/metro cards;
- Carpools;
- Taxi vouchers;
- Bus tokens; and
- Cash for transportation reimbursement.

# SETTING UP A CAB

## Module 1



### *Prizes*

Some sites offer prizes during CAB meetings. There may be site restrictions about monetary incentives (money). This means that although the site is not allowed to hand out money, they may be able to give out goods. One site raffles off prizes during CAB meetings. Raffle prizes include movie tickets, restaurant gift cards, and candy. Prizes are a great way to give something special to CAB members and show appreciation.

Prize giveaways are especially useful for sites with restrictions about monetary incentives. Remember, prizes don't necessarily need to be purchased with CAB funds. It may be possible to talk to local businesses and ask for donations. For example, try talking to a local movie theatre. They may be able to donate movie tickets or food vouchers. Be sure to check with site staff about options for prizes.

### *Money and Gift cards*

Some site CABs provide compensation (money) for CAB members who attend CAB meetings regularly. Some sites are only able to compensate CAB leadership. Availability of monetary compensation varies by site. Sites may compensate CAB member anywhere from once per year to once per meeting. As mentioned earlier, there may be site restrictions about monetary incentives.

Although sites might not be allowed to hand out money, they may be able to give out gift cards. CABs give out gift cards for movie theatres, restaurants, and stores. Be sure to check with site staff about options for monetary compensation and gift cards.

# SETTING UP A CAB

## Module 1

### *Networking, Access, and Guest Speakers*

CAB meetings may give CAB members the chance to meet other study caregivers and/or participants. The CAB provides a place for CAB members to learn and give feedback about the study. At many sites, site staff attend CAB meetings. This allows CAB members to meet the researchers and ask important questions ([see page 37 for more information on site staff communication](#)).

“My favorite parts about my CAB are networking, meeting new people, being involved, and making an impact on current and future research. [ feel like I make a difference.”

- CAB Member

Many sites offer health educational materials to CAB members during CAB meetings ([see page 60 for more information on health educational material availability](#)).

Some site CABs invite guest speakers to present a topic of interest during CAB meetings. CAB members are given the opportunity to learn about a topic from an expert in the field.

### *Parties*

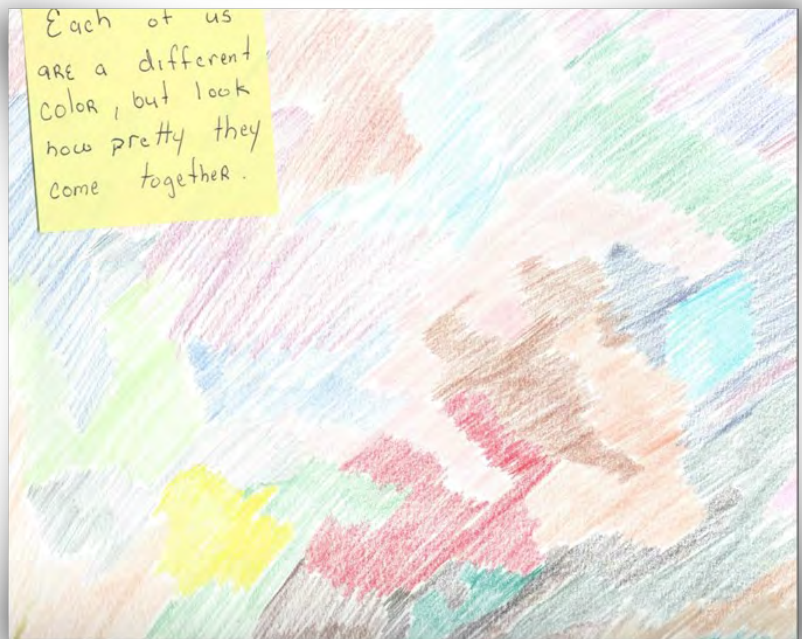
Some CABs throw parties for the CAB. CAB members and their family members are invited to come parties. Parties may be expensive, so be sure to check with the site staff about funding options for parties.

# SETTING UP A CAB

## Module 1

### *Leadership, Professional Opportunities, and Workshops*

Many site CABs have leadership positions. This may include an elected CAB Chair and Vice Chair. Leadership experience may help CAB members in their professional lives. Some sites even offer professional opportunities to CAB members. This may include employment opportunities at the site and invitations to professional conferences.



Some sites offer workshops to CAB members during CAB meetings. One site held a writing workshop to help CAB members improve their writing skills. Funds might not necessarily be needed to hold workshops for CAB members. Think about the individuals and resources available at the site. Some sites are connected to universities. If possible and if it's permitted by the CAB, students may be willing to hold a workshop during a CAB meeting.

### *Emotional Support*

CABs often provide a place for HIV-infected and affected people to give and seek emotional support. Many CAB members have stated that their CABs also function as support groups. Talk to site CAB members about their preferences for meeting organization and structure. Think back to your site CAB mission statement: is part of the CAB's mission to support one another?

# CAB STRUCTURE

## Module 2

### Location—Where to Hold Site CAB Meetings

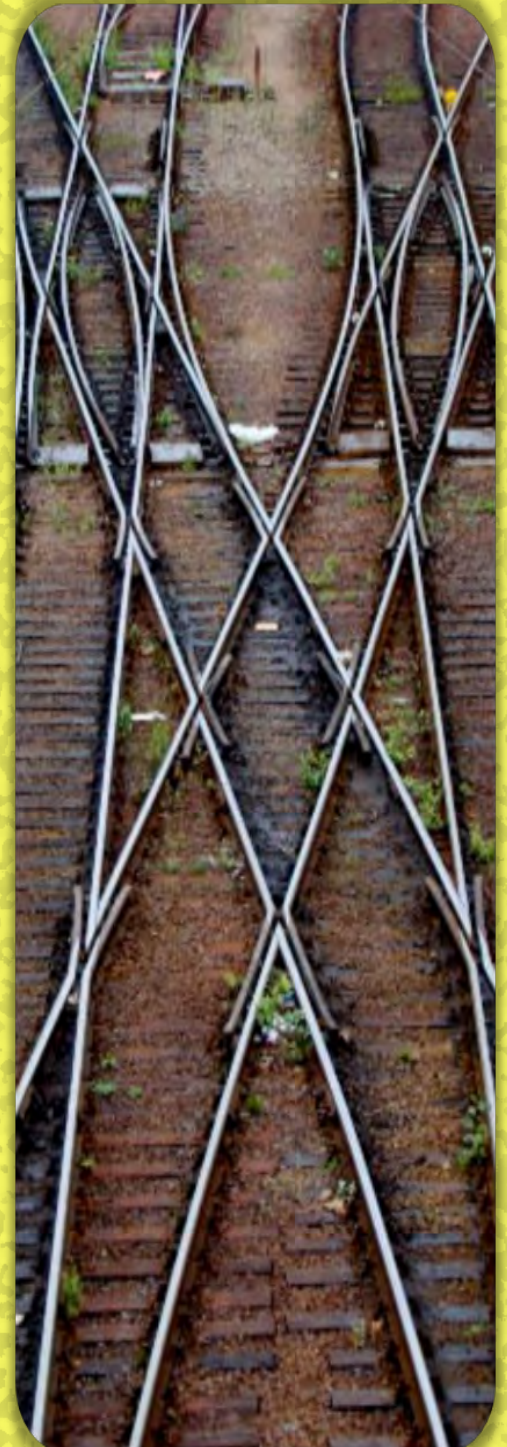
The location of site CAB meetings varies by site. There are many issues to consider when choosing a site CAB meeting location. These issues include:

- Space availability;
- Distance from public transportation;
- Parking;
- Safety; and,
- Privacy.

#### *Space Availability*

Most PHACS Site CABs meet at the clinic site. Many sites choose to hold meetings at the clinic because it is convenient and familiar for CAB members. At the clinic, the CAB may also have access to office supplies, computers, and projection equipment.

One site CAB holds its meetings at the clinic because of the availability of rooms. The CAB uses a large room for the CAB meeting that can accommodate small or large groups. The waiting area outside the room is used for dinner before the meeting. Some site CABs refrain from using public spaces like waiting rooms for confidentiality purposes.



# CAB STRUCTURE

## Module 2

The waiting area is also used as a homework/play space for CAB members' children. An additional clinic room is used as a baby changing room. Many CABs recommended holding meetings in a large space. A larger room can help accommodate both CAB members and their children.

### *Access to Public Transportation*

Choose a location that is accessible by public transportation. This is important for CAB members who primarily rely on public transportation. It is also important because many sites may have reimbursement or voucher options for public transportation to and from CAB meetings.

### *Parking*

Just as important as access to public transportation is parking availability. Select a location with plenty of parking. If there is a fee for parking, check with your site about parking reimbursement. Many site CABs hold their meetings at the clinic because parking for clinic patrons is free.

### *Safety*

Choose a safe location and time. This may include not holding meetings late in the evening. Many sites choose to hold their meetings at the clinic because the location is safe. Keep in mind that many CAB members may bring their children to meetings. If this is the case, choose a location that is safe for children as well as adults. If the location has parking, make sure CAB members are safe as they walk to and from the building.

# CAB STRUCTURE

## Module 2

### *Privacy*

Some participants in HIV studies may not be comfortable disclosing their HIV statuses. Therefore, it is important to choose a meeting location that does not inadvertently disclose CAB members' statuses. For example, try to choose a location that does not have HIV posters or signs.

Keep in mind that even the name of the clinic could cause inadvertent disclosure. If the clinic's name has anything to do with HIV, consider asking site staff about other locations within the institution that might be available for site CAB meetings.

It is best to consult with site CAB members about choosing a realistic location that is both convenient and private.

### **Meeting Frequency and Length**

How often a CAB meets depends on the availability and need of the CAB members. It also depends on how often the CAB receives study updates. Many CABs meet once a month. CABs that meet monthly typically meet for 1-2 hours. On the other hand, other CABs meet 1-2 times a year. If the site CAB is only able to meet a few times a year, consider holding longer meetings to allow enough time to discuss important issues.





# CAB STRUCTURE

## Module 2



Some CABs only meet when there are study updates to review. However, many CABs have noted that it is important to meet on a more regular basis. A regular schedule allows CAB members to meet and socialize in a structured way. It also allows the CAB to talk about issues that might come up unexpectedly. Hosting regularly scheduled meetings also helps the CAB to invite guest speakers for future meetings because it allows the CAB to present potential guest speakers with options for future dates. It is easier for a guest speakers to plan on attending future CAB meetings knowing that meetings take place on consistently scheduled dates. In addition, having regularly scheduled meetings helps CAB members keep in touch and stay engaged in the CAB.

It may be helpful to schedule CAB meetings around a meal, but be mindful of time. This creates a perk for CAB members and allows meetings to be scheduled during CAB members' typical breaks in the day. Many site CABs choose to meet during a weekday around lunch time. Meeting at this time allows the CAB to have lunch together. It also helps CAB members meet while children are in school. Other Site CABs meet in the evening and provide dinner to accommodate members who work.

Site CAB meetings should be held on days/times that work for the most members. It is best to consult with CAB members about scheduling regularly scheduled CAB meetings.

# CAB STRUCTURE

## Module 2

### Number of CAB Members

The number of CAB members in a site CAB depends on the size of the Site. PHACS site CABs currently report having as few as three members up to as many as 40 members.

One site CAB recommends smaller numbers – to this CAB, more is not always merrier. This group feels that with more CAB members, there may be more disagreements. It is harder to come to decisions with larger groups because there are more opinions to consider. Other smaller site CABs believe that smaller numbers help manage discussions.

Another site CAB recommends larger numbers. This group feels that more members allow for greater diversity. It also helps CAB members connect to a larger HIV-affected community. This allows more members to share opinions, resources, and support. Each site CAB can weigh the pros and cons and decide for itself how large or small it would like its group to be.

Activities need to be structured depending on the number of site CAB members. Smaller numbers may be better for personal and intimate discussions. Larger numbers allow for greater diversity and more connections.

It may not be possible to control the number of members in a site CAB, but it is possible to control CAB activities. Large CABs can break into smaller groups to allow for more intimate discussions. Smaller CABs can appoint representatives to serve on other CABs and committees at the site or in the community. These CAB members can report back from the other groups, allowing them to represent a larger number of community members.

# CAB STRUCTURE

## Module 2

### Site CAB Meeting Leader

It's up to each site CAB to determine which person will lead the meetings. At many sites, the staff CAB Liaison runs the meetings ([additional information about staff CAB Liaisons may be found on page 29](#)). Other people serving as site CAB meeting leaders might include:

- IMPAACT RCAB Representatives;
- Case managers;
- Site CAB Chair and Vice-Chair;
- Program coordinators;
- Nurses; and
- Other site staff members.

However, at most sites, running Site CAB meetings is a group effort.

At one site, the peer navigator (who is also a member of the community) leads the meetings. The program coordinator (who is also a nurse) co-leads the meetings. The program coordinator helps provide information about health services at the site. Although these two people lead the meetings, they rely on participation from all Site CAB members to set the agenda. The peer navigator truly understands the needs of the community because she is a community member herself. She encourages and inspires members to share personal information that help their voices be heard.



# CAB STRUCTURE

## Module 2

One site's CAB meetings are typically run by the Study Coordinator and CAB Liaison. However, the CAB frequently invites guest speakers. The guest speakers present different topics of interest to the CAB. This CAB believes that having different presenters works very well to keep the CAB's attention. It is also helpful for skill-building among group members.

It may be very helpful to run Site CAB meetings using a team approach. Overall, it is most important to pick a site CAB leader who the CAB members trust. Some sites vote on a site CAB leader. Together, the CAB can determine how long the site CAB leader should serve. Other sites ask for volunteers to serve as site CAB leaders.

Many site CABs thrive under a CAB-appointed leader. It is important to come up with a selection process that is deemed appropriate and fair to all CAB members. Before holding an election or selecting volunteers, work with the CAB to come up with a selection process.

Ask the CAB to define the roles and responsibilities of the site CAB leader. It's helpful to ensure that potential CAB leaders understand the commitment associated with leadership roles.

### **CAB Chair Roles and Responsibilities**

---

1. CAB Chair creates meeting agenda.
2. CAB Chair runs meetings.
3. CAB Chair helps recruit new members.

# CAB STRUCTURE

## Module 2

### CAB Liaison

Many sites have a site staff CAB Liaison. Responsibilities of the CAB Liaison vary across sites. At several sites, this is a paid position. The CAB Liaison typically acts as a:



#### *Meeting Coordinator*

At one site, the CAB Liaison is the coordinator of Site CAB meetings. The Liaison drafts the agenda and orders food for the meetings. The Liaison also sends out reminder letters, arranges for transportation, and books the meeting room. The Liaison also coordinates all other CAB special projects.

At another site, the CAB Liaison recruits site CAB members. The Liaison also coordinates the meetings with help from CAB members. The Liaison makes and sends out flyers about the meeting. She also calls CAB members to encourage them to attend the meetings and to find out if they need help with transportation.

# CAB STRUCTURE

## Module 2

### *Intermediary*

The CAB Liaison often acts as an intermediary. He/she is the connection between the CAB members and the site staff. This means that at many sites, the Liaison evaluates the needs of the CAB and larger community. He/she then communicates these needs and questions to the site staff and research team. The Liaison communicates clearly with the community and facilitates interaction with other research study groups.

### *Resource*

The CAB Liaison might also be a resource for CAB members. At one site, the Liaison serves as a resource for CAB members by answering questions regarding the study. The Liaison has a functional understanding of the research process. She shares this information with the CAB. This Liaison also provides opportunities for CAB members to learn about health topics.

Most sites with CAB Liaisons report that they contribute to the effectiveness of the CAB. The Liaisons are able to both oversee the CAB and work with site staff. They are also able to support site CAB leadership to help CAB meetings run as smoothly as possible.

### **Site Staff Involvement in the CAB**

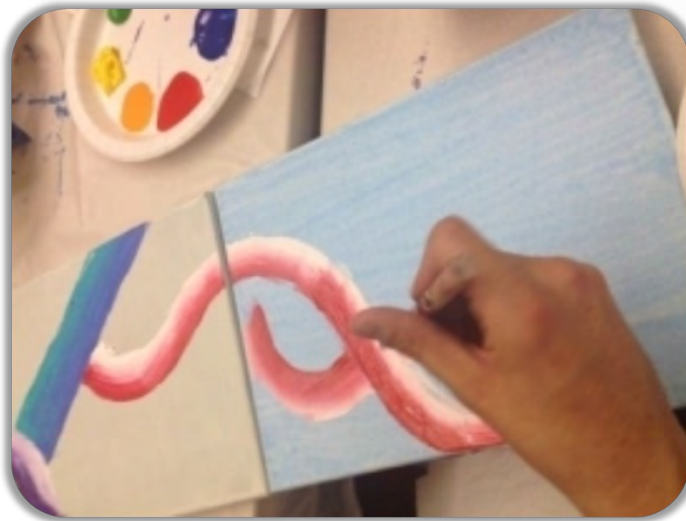
Many Site CAB members and CAB Liaisons feel that it is important for Study Coordinators and Principal Investigators to be involved in the CAB. They also believe it is important for these staff to attend site CAB meetings whenever possible.

# CAB STRUCTURE

## Module 2

However, other site CABs feel that site research staff should not attend site CAB meetings. They feel that their attendance may disturb the usual flow of meetings. CAB members may feel nervous in front of the researchers and unable to speak their minds.

At most sites, the Study Coordinators and Principal Investigators do not attend every CAB meeting. At some sites, they attend meetings as needed. For instance, they might attend CAB meetings to present new results of studies when they are released.



At other sites, site staff attend CAB meetings on a more regular basis. They check in with the CAB every few meetings. This type of schedule can be helpful for CAB members because they can plan for these meetings. By knowing ahead of time when the researchers are scheduled to attend the meetings, CAB members can bring questions and come prepared.

Site staff CAB involvement may play a crucial role in:

- Dissemination of information;
- Study feedback;
- Meeting planning and coordination; and,
- Study retention.

# CAB STRUCTURE

## Module 2

### *Dissemination of Information*

At several sites, site research staff present updates and scientific information to the CAB during meetings. These researchers are able to talk about study findings in an easy to understand manner. They may present participant summaries, new protocols, health news, and/or community events. Many CAB members say they like when site staff attend meetings. This is because they have the chance to ask the site staff directly about questions they may have.

### *Study Feedback*

At some sites, site staff attends CAB meetings in order to get feedback from the community about the study. This may include feedback about a protocol, medical procedures, and general study operations. In this way, the CAB serves as the link between the researchers and the community/study participants.

### *Meeting Planning and Coordination*

At some sites, site staff members assist with meeting coordination. They order meals for the meetings and coordinate childcare. They also handle transportation requests, set up the meeting room, make and hand out the agenda, and remind CAB members about upcoming meetings.

### *Retention*

Some site CAB members feel that site staff involvement is important for retention. Many CAB members enjoy interacting with their site staff members in a non-clinical setting. It helps CAB members see and feel that their thoughts and feedback are important to the researchers.



# CAB STRUCTURE

## Module 2

Many site staff also believe it is helpful for site staff to attend CAB meetings. It may be helpful for the researchers to develop relationships with the site CAB. This allows CAB members to learn from the researchers and take the information back to the community. It also allows CAB members to give feedback about the study from the community directly to the researchers.



It is important to talk to CAB members about their preferences. Although it may be helpful for the CAB to learn from researchers, it may also be important for CAB members to interact among themselves.

In addition, be mindful that site staff may not be available for any or all CAB meetings. If site staff involvement is a preference for the CAB, ask CAB leaders or Liaisons to let site staff know. If they are unavailable to attend meetings, they might be willing to find an alternative way to be involved in the CAB.

If site staff are available for meetings, it is helpful to make their attendance predictable to the CAB. This can help CAB members prepare better for meetings. It may be helpful to consider asking site staff members to be present for every other meeting. This approach allows CAB members to interact with and learn from site staff, but also gives CAB members time to interact among themselves.

# COMMUNICATION

## Module 3

### Confidentiality

Maintaining confidentiality is one of the most important parts of a successful CAB. CAB members should feel safe at site CAB meetings. Everything discussed in a CAB meeting should be kept confidential. This includes HIV statuses of each CAB member.

Recognize that not all CAB members may feel comfortable disclosing their statuses. They may be comfortable disclosing in some spaces, but not others. For some CAB members, CAB meetings may be the only space where they feel comfortable talking about HIV.

Many site CABs make rules to help keep CAB meetings confidential. CAB members' needs for privacy may be different at each site. One site suggested that site CABs create a confidentiality policy together during a CAB meeting. Once the policy is made, it may be helpful to review the policy before every meeting. Think of a confidentiality agreement as ground rules for the CAB. Some site CABs have set the following general ground rules:

- Respect one another's opinions;
- Respect one another's time – notify a CAB member or liaison as early as possible if unable to attend a meeting;
- Do not interrupt when another member is speaking;
- Phones should be put on vibrate or silent during meetings;
- Any personal information, including HIV statuses, shared at the meetings stays within the group; and
- Questions are always welcome at the appropriate time.

# COMMUNICATION

## Module 3

Since confidentiality can be a very private subject, it may also be helpful to put out a box for anonymous comments when creating a confidentiality policy. This allows CAB members to contribute to the confidentiality policy without disclosing their personal opinions aloud. This system can also be used to give general comments about other issues that come up during regular CAB meetings. Before putting out a box for anonymous comments, talk to the CAB about their preferences for what to do with the comments that are submitted. It may be helpful for the CAB to consider that comments be read aloud for the group to discuss during future meetings.

**“Everyone has a voice  
and a point, but all  
cannot be heard at the  
same time.”**

**-Kim**

Several site CABs ask CAB members to sign confidentiality agreements. Most site CABs ask CAB members to sign the confidentiality agreement just once, although many site CABs recommend reviewing the CAB confidentiality policy at least once a year. The agreement should be re-signed if the policy changes.

At one site CAB, the confidentiality agreement is included in a CAB member contract. All new CAB members must sign the CAB member contract before attending site CAB meetings. In addition, this site CAB has visitor contracts for potential members or visitors to sign before attending meetings. The visitor contract was suggested by a CAB member as a way of helping the space feel safe. It helps allow potential CAB members and CAB family/friends to attend meetings while keeping the meeting content private (see [Appendix II for a CAB member contact template](#) and [Appendix III for a visitor contract template](#)).

# COMMUNICATION

## Module 3

Some site CABs purposely do not have a sign-in sheet for site CAB meetings. This helps keep meeting attendance private. Keep in mind that CAB meetings may be the only place some CAB members feel comfortable disclosing their statuses. Many CAB members have chosen to not acknowledge each other when they see each other in public out of respect for one another's confidentiality. This can be important to discuss as a group.




Meeting location is important in maintaining confidentiality. If the clinic is a known HIV/AIDS treatment center, it may be helpful to hold meetings elsewhere. There may be available rooms within the clinic/hospital, or at a nearby building that is owned by the site institution. Talk to site staff about options for CAB meeting locations.

Information about site CAB meetings can possibly disclose members' statuses. Some sites choose not to use "HIV" or "AIDS" on their flyers and meeting invitations. At some sites, because site CAB meetings take place at the clinic, there are no HIV posters or information in the waiting room. This is because some CAB members' family members and/or children might not know their statuses. Timing of meetings can also help maintain confidentiality. One site suggests holding meetings on the weekend if held at the clinic. At this site, there aren't as many people in the clinic on the weekends.

# COMMUNICATION

## Module 3



It is very important to note cultural differences and similarities among CAB members and potential CAB members. Some families may be reluctant to participate in site CABs, or even to seek support. They may worry that their local community may find out about their statuses. They may also fear that their community of friends, family, and others in their home country would also find out, and that this would be a source of potential shame. It may be helpful to talk to site staff members and community liaisons about finding alternative ways to support these families.

Talk to site CAB members and site staff about creating a confidentiality policy. Site staff members take many measures to ensure study participants' confidentiality. They may be able to help apply some of their practices to confidentiality within the site CAB.

### **Connecting the Site CAB to the Site Staff**

It is important for the site CAB to communicate with site staff. Many site CABs select one person to be the liaison between the site CAB and the site staff. At these sites, the CAB Liaison talks with site staff by email and phone between site CAB meetings. Some sites elect a site staff member, such as a Peer Educator or Navigator, to serve as the CAB Liaison.

# COMMUNICATION

## Module 3

It is important to talk with CAB members about what information they are comfortable sharing with site staff. Many site CABs like to inform site staff about the topics they are interested in learning about. Site staff may be able to connect them to resources, guest speakers, or even present the material themselves.

Communicating with site staff can be very beneficial for issues having to do with CAB meeting logistics, such as:

- Funding;
- Meeting space availability;
- Meeting materials (pens, papers, projectors, etc.);
- Incentives;
- Providing meals; and/or
- Childcare during meetings.

Site staff may also be very helpful in recruiting new CAB members. They may be willing to play a role in recruitment. Ask the CAB Liaison or CAB Leadership to talk to site staff about recruitment strategies ([see page 7 for more information about recruitment](#)).



# COMMUNICATION

## Module 3



Perhaps one of the most important reasons for communication between the site CAB and site staff is to provide community feedback and to answer questions/concerns about the research study.

One of the CAB's missions is to provide community feedback about research studies in order to optimize them for the participants and families who are most affected by them. Therefore, it is important that CAB members feel that their opinions are being heard. Talk to site staff and CAB members about the most appropriate way to provide feedback ([see page 37 for more information about site staff involvement in the CAB](#)).

One site's CAB Liaison shares site CAB meeting flyers with site staff. Site staff members are encouraged to hand out flyers to interested families. Be sure to check with CAB members and potential CAB members about their preferences for printed materials. Keep in mind that for confidentiality reasons many CAB members may not feel comfortable receiving printed materials in the mail or taking printed materials home. Ask CAB recruiters or site staff members to review flyers with interested families, but be aware that they may not feel comfortable taking flyers home ([see page 7 for more information about site staff involvement in recruitment](#)).

# COMMUNICATION

## Module 3



Other site CABs share their agenda with site staff members. Talk with site CAB members and site staff about sharing site CAB materials. If CAB members are comfortable, it may be helpful to share meeting minutes or agendas with site staff to keep the staff informed about general CAB updates. It may also be helpful to use minutes as a platform to sharing community feedback about the research study.

At several sites, site staff members communicate directly with the site CAB. Site staff may attend meetings. They may also help with meeting planning and preparation. Many sites recommend reaching out to site CAB members over the phone instead of email. Talk with site staff about the most effective way to communicate between the site staff and the site CAB.

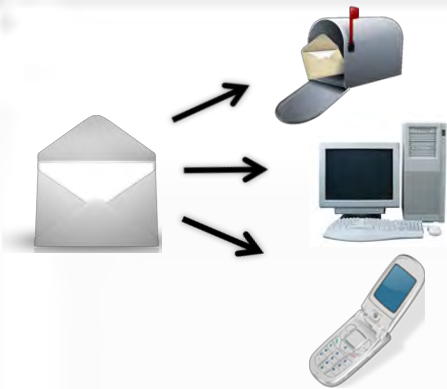
### Communicating about Site CAB Meetings

Most site CABs find ways to make each other aware of upcoming site CAB meetings. CAB members communicate about meetings by phone, mail, text, and email. At most sites, the CAB Liaison and/or CAB Leadership are responsible for contacting CAB members. One site decides on a meeting schedule during the first meeting of the year. Schedules are handed out to all participating CAB members. If there is a change in schedule, the CAB starts a phone triage. To start the triage, the CAB Liaison calls the first CAB member on the CAB contact list, who then calls the next CAB member. If unable to reach the next CAB member, the first CAB member continues to move down the list, calling CAB members to start the triage and spread the word.



# COMMUNICATION

## Module 3



At another site, the CAB Chair and CAB Liaisons email meeting reminders to CAB members. If necessary, the reminders are also sent by phone and regular mail. Remember, not all CAB members may be comfortable receiving CAB-related mail at home. Ask CAB members about their preferences for contact outside of site CAB meetings.

At some sites, the site support staff is solely responsible for all mailings and phone contact with CAB members and study participants.

### Connections with Other Networks

Many site CABs welcome members from other similar research networks. Some sites share resources and information with other groups at their institution. One site CAB shares information about events in the community, job postings, and scholarships with a local HIV youth leadership council.

More often than not, there is more than one research network within the same institution. This may make it easier to invite members from other networks to participate in CAB meetings. The purpose of connecting with other networks is to disseminate important research information throughout the community.

It is important to connect with other networks in order to stay up to date on current community resources. For more information about the different research networks within your institution, contact site staff members.

# MEETING CONTENT

## Module 4

### Today's Agenda



### CAB Meeting Agenda

No matter how often they meet, all site CABs get together for meetings at least once a year. Most CABs meet on a regular basis - about once every month. CAB meetings allow CAB members to interact with each other, learn about new information, support each other, and share resources. What goes on during CAB meetings varies by site. There are no rules about how CABs run their meetings. It is up to CAB members and CAB liaisons to plan meaningful CAB meetings.

Most site CABs recommend coming up with an agenda for site CAB meetings. Some site CABs send out the agenda ahead of time. Others hand out the agenda at the meetings. Some site CABs email the agenda to CAB members, mail the agenda to CAB members, or write it on flyers to post in the clinic or hand out to potential CAB members.

Most sites recommend asking the CAB to suggest topics for agenda. One site CAB decides on topics for the next year during their December meeting. Consider setting aside time every few meetings to come up with topics for future CAB meetings.

# MEETING CONTENT

## Module 4

CAB leaders (CAB Chairs, CAB Liaisons, site staff liaisons, etc.) typically put the agenda together. One site CAB member believes that it is helpful to distribute the agenda in advance of CAB meetings. It may also be helpful to set the agenda for the next meeting before CAB members leave the meeting. This is particularly helpful for guest speaker presentations. It allows CAB members to prepare ahead of time and come up with important questions. One site CAB recommends placing important items at the beginning of the agenda in case time runs out. Generally, site CAB agenda items focus on the following broad topics:

- *Welcome and Socialize*
- *Participating Research Studies*
- *HIV/AIDS Research and News*
- *HIV/AIDS 101*
- *Representative Updates*
- *Advocacy and Events*
- *Movie Screenings*
- *CAB-Specific Topics*
- *Open Forum*
- *Support*

### *Welcome and Socialize*

Many site CABs schedule their meetings around a meal. This allows CAB members to unwind and socialize before the meeting. Most site CABs start the meeting with introductions and announcements. It provides CAB members an open opportunity to share about themselves before diving into the agenda. Since many topics covered during CAB meetings can be very personal, it is important that CAB members feel somewhat comfortable with each other.

If there are new CAB members, or if the CAB could benefit from getting to know each other better, consider starting the meeting with an icebreaker. Icebreakers are great ways for CAB members to get to know each other. Icebreakers may also help CAB members feel more comfortable participating in discussions during meetings.

# MEETING CONTENT

## Module 4

**HELLO**

My name is

**CAB  
MEMBER**

The best icebreaker exercises vary depending on the size of the CAB and their familiarity with each other. If the CAB is large in number and energetic, consider trying the “Bingo” icebreaker. This involves a little bit of preparation work ahead of time. Create a list of characteristics such as “Likes spicy food,” or “Has a child participating in a research study,” etc. Print copies of the lists, and hand them out to the CAB. Allow ten minutes for CAB members to

visit with each other and find one person to match each of the characteristics. Once one person’s list is complete, or ten minutes are up, ask CAB members to share something interesting they learned about someone else ([see Appendix I for a Bingo Icebreaker Game template](#)).

Icebreakers don’t have to be complicated. If the CAB is small, not too energetic, or there isn’t enough time, try a simple icebreaker. Go around the room and ask each CAB member to introduce themselves using their real name or a nickname. Each time the group participates in this exercise, ask each CAB member to answer a different question like “name a favorite food,” or “name your favorite summer activity.” Avoid serious questions that might cause anxiety; keep it light.

Below is a link to instructions for ten fun icebreaker exercises:

Top Ice Breaker Games for Adults: <http://adulted.about.com/od/icebreakers/tp/toptenicebreakers.htm>

# MEETING CONTENT

## Module 4

### *Participating Research Studies*

Most site CABs try to focus some part of their CAB meetings on learning and/or giving feedback about research. This includes studies that CAB members or their family members are participating in. Some site CABs spend time reviewing protocol and substudy updates.

Many CABs find it helpful to start by reviewing a participant research summary with the CAB. At some sites, the site Principal Investigator (PI) may attend meetings to review participant research summaries/protocol updates and answer questions.

If your site PI is unable to attend CAB meetings, try reviewing the participant research summary together as a CAB. Write down any questions. Ask the site CAB Liaison or CAB leader to share the questions with the site PI. During the next site CAB meeting, the CAB can review answers ([see page 62 for more information about participant research summary reviews during CAB meetings](#)).

### *HIV/AIDS Research and News*

Many site CABs enjoy learning about the latest in HIV/AIDS research and news. Some site CABs discuss research findings together. Other CABs invite guest speakers, including site staff, to review news and answer questions.

Encourage site CAB members to look for research and news and bring it to site CAB meetings. Consider setting aside ten minutes at every meeting to talk about the latest news. Ask site CAB members to get involved by searching for news articles. Consider alternating site CAB member news finders each week so each CAB member can get involved in this activity.

# MEETING CONTENT

## Module 4

Some CAB members may even be interested in presenting articles to the group. Keep in mind that news articles can be complicated and sometimes misleading. Talk with CAB liaisons and CAB members about creating guidelines for reviewing articles. It may be helpful to suggest that CAB members only search for articles in specific credible websites, or that all news articles be reviewed by the CAB liaison or a site staff member before presenting to the CAB.

Below are a few credible sources for the latest in HIV/AIDS news:



AIDS.GOV blog: <http://blog.aids.gov>

nam aidsmap: <http://www.aidsmap.com/latest-news>

Center for Disease Control and Prevention HIV/AIDS Daily News: <http://www.cdc.gov/hiv/dailynews>

### *HIV/AIDS 101*

In addition to covering HIV/AIDS research and news, many site CABs find it helpful to occasionally talk about basic information about HIV/AIDS. Site CABs cover topics such as HIV disease progression, transmission, and medication adherence.

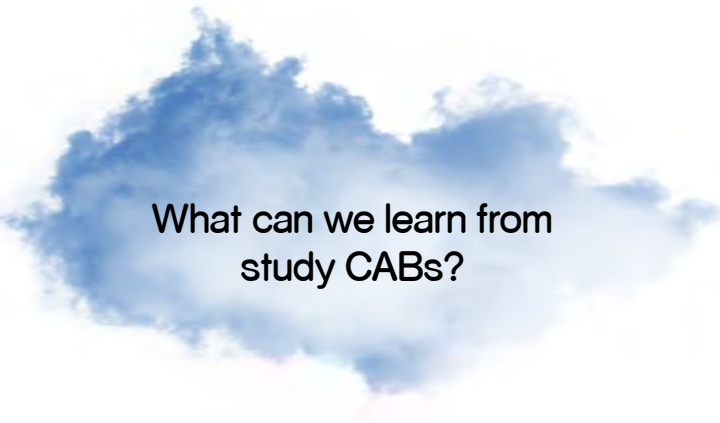
Since HIV/AIDS 101 presentations are for educational purposes, it is important to review this information with a clinical expert. If your CAB is interested in learning more about HIV/AIDS, contact site staff members about setting up a presentation with a guest speaker.

# MEETING CONTENT

## Module 4

### *Representative Updates*

In most site CABs, only one or two members serve on a study-specific CAB, like the PHACS CAB. Site CABs are asked to choose a volunteer to attend study CAB conference calls and report back. These members are the site CAB representatives. Many site CABs use meetings as an opportunity for these representatives to report back from the conference calls or meetings they attend.




What can we learn from study CABs?

Remind members that CAB representatives must represent the site CAB in the larger PHACS CAB. Typically during study-specific CAB calls, site CAB representatives from each study site call into a conference call line to talk about PHACS CAB and study-related information. There are many opportunities during these calls for CAB representatives to give feedback about study-related topics from their site CAB's perspective. This means representatives should also make the site CAB aware of any outstanding PHACS CAB issues that may require site CAB input and/or feedback.

Site CAB representatives, especially new ones, may be nervous or anxious to speak up during a conference call. There are many ways to participate that don't include speaking up. Many site CABs invite the site CAB representative to join the call with a site staff member at the clinic. If the representative is more comfortable organizing their thoughts with a site staff member, the site staff member can speak up and give their feedback if desired. Site staff may also be able to clarify any challenging topics.

# MEETING CONTENT

## Module 4



It is also possible that site CAB representatives may not have time to process their thoughts during the call time. He/she may also want to talk about the issues with the site CAB before giving feedback on the study-specific CAB call. This is perfectly okay! Site CAB representatives (site CAB members who serve on the study-specific CAB) may contact the study-specific CAB Liaison via phone, mail, or email with any follow-up questions or feedback. Some study-specific CABs, like the PHACS CAB, may send out anonymous online surveys after the conference calls. This gives site CAB representatives the opportunity to share their thoughts privately without mentioning their name.

Keep in mind that other site CAB representatives are often willing to offer support or advice to CAB members. Contact the study-specific CAB Liaison about connecting your site CAB representatives to other CAB members.

### *Advocacy and Events*

Many site CABs participate in local events having to do with advocacy, community outreach, and health education and promotion. During some site CAB meetings, CAB members review recent events or suggest events for CAB members to attend.



# MEETING CONTENT

## Module 4



### *Movie Screenings*

There are several movies having to do with HIV/AIDS that are educational and/or thought provoking. Some site CABs occasionally show HIV/AIDS-related films to prompt discussions during meetings. Consider preparing discussion questions for after the movie. If the CAB agrees to talk openly, allow time after the movie for an open

discussion. Follow the link below to see a list and descriptions of movies having to do with HIV/AIDS:

Positive Living Association, HIV/AIDS in Movies: <http://pozitifyasam.org/en/hiv-aids-and-more/hiv-aids-in-movies.html>

### *CAB-Specific Topics*

Many CABs recommend spending at least one meeting a year covering CAB-specific topics. This may include revisiting the site CAB confidentiality policy, talking about ways to improve the CAB, and checking in with CAB members about meeting structure, location, and time.

It may be helpful to create a survey for CAB members to give feedback about CAB specific topics, especially if there are a large number of members. Hand the survey out at the end of a meeting and review it at the beginning of the next meeting. This allows members to comment and give feedback anonymously (if they choose) and it can also help draw attention to specific issues.

# MEETING CONTENT

## Module 4

### *Open Forum*

Site CABs can greatly benefit from structure in their meeting planning. However, some CAB members may feel unable to bring up important questions that aren't on the agenda with this format. Many site CABs recommend making time for an open forum every few meetings (approximately 10-15 minutes). Let CAB members know that no topic is off limits during these discussions.

It may be helpful to hold these discussions during a meeting where a site staff member is present in case CAB members bring up issues that may require medical attention or referral. However, some CAB members have expressed the desire to be able to talk openly with CAB members only. If this is the case, consider asking site staff to leave the room during this time, but be available if issues should come up.

Ask the site CAB their preferences for open forum discussions. Since site CAB members may not feel comfortable stating that they'd rather talk among themselves, consider passing out a quick anonymous survey to be reviewed by CAB Leadership/Liaisons.

### *Support*

Although CABs are typically not the same as support groups, many CAB members find support in their CABs. One site CAB uses 15 minutes at the end of CAB meetings as a support session. Similar to an open forum, these 15 minutes are specifically for members to share stories and offer support to each other. Just like open forum discussions, CAB members may feel more comfortable holding a support session among themselves without site staff present (see "Open Forum" above for more options for these types of sessions).

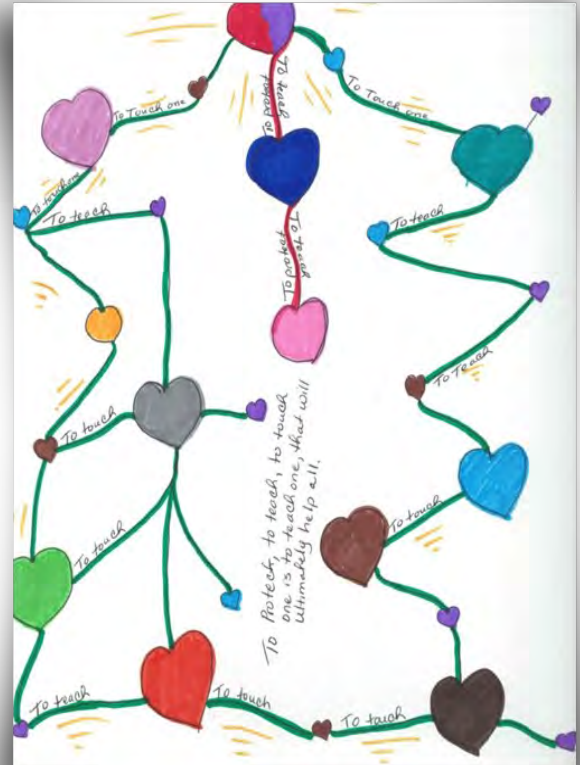
# MEETING CONTENT

## Module 4

### Site CAB Discussion and Guest Speaker Presentation Topics

Site CABs cover a wide range of topics for discussion during CAB meetings. Some CABs choose to review topics with site staff, invite guest speakers, or talk about the issues among themselves. Below is a list of topics from past PHACS site CAB discussions:

- Criminalization of HIV;
- Health care reform and HIV;
- Stigma;
- How to get involved in HIV/AIDS advocacy;
- Different types of advocacy;
- Medication and HIV treatment;
- Nutrition and HIV;
- Neurocognitive impact of HIV;
- AIDS in children and adults;
- Alternative medicine;
- Alcohol and HIV;
- Gene therapy studies and HIV control;
- HIV cure;
- Losses to follow-up in HIV care;
- National HIV testing day;
- HIV-positive men and adoption;
- Serodiscordant couples;
- Mother-to-child transmission;
- Shame and shame resilience;
- Safe sex;



# MEETING CONTENT

## Module 4

Empowered

Inspired

Hopeful

- Microbicides;
- Substance use and HIV;
- Adolescent adherence;
- History of Ryan White;
- Community outreach – HIV testing and care;
- Disclosure;
- Informed consent;
- Research ethics;
- Families affected by HIV;
- Understanding abuse;
- Healthy Relationships
- Confidentiality; and
- Support systems.

### Ending the Meeting

It can be very helpful for CAB members to vocalize how they're feeling after CAB meetings. The PHACS Young Adult Community Advisory Board (YACAB) does this at the end of YACAB conference calls. Each YACAB member gets a chance to sum up how they're feeling in one word or phrase. Words from YACAB calls have often included empowered, inspired, and hopeful. This gives CAB members the opportunity to connect to each other and the meeting content. This practice can be particularly helpful for intense or emotional discussions.

# MEETING CONTENT

## Module 4

### Did you Know?

Many CAB members prefer to learn from guest speaker presentations.

### Tips for Monitoring Guest Speaker Presentations

Many CAB members highly recommend inviting guest speakers to site CAB meetings. For some CAB members, guest speaker presentations are their favorite parts of meetings.

Several site CABs recommend appointing a timekeeper for guest speaker presentations. This is especially helpful for guest speakers who may need to leave at a certain time, or for topics that prompt a lively and lengthy question-and-answer discussion. Ask for timekeeper volunteers, or rotate timekeepers each meeting.

Write time increments on signs (i.e., 10 minutes, 5 minutes, 1 minute, etc.). Ask the timekeeper to sit in the back of the room and flash the signs to the speaker when necessary. It is helpful to seat the timekeeper in the back of the room so signs aren't distracting CAB members.

Many site CABs recommend handing out copies of presentations to CAB members ahead of time. This gives CAB members the chance to become familiar with the material before the presentation. It also allows CAB members to follow along with the presenter. Some site CABs mail or email the presentations to CAB members ahead of time. Keep in mind, some CAB members may not want CAB materials to be mailed to their home.

# MEETING CONTENT

## Module 4

### Questions for Guest Speakers

1. Where can we find more information about similar studies?
2. Who can benefit from this information?
3. When will the final results of the study be released?
4. What is the main takeaway from this study?
5. What are the next steps?

Talk with site CAB members about preferences for receiving CAB meeting materials. If possible, ask the guest speaker to distribute the presentation to CAB Leadership or Liaisons prior to the meeting.

In addition to reviewing material ahead of time, many site CABs find it helpful to come up with questions for guest speakers before the presentation. This allows the CAB time to come up with meaningful questions. If possible, it is also helpful for the speaker to review questions ahead of time.

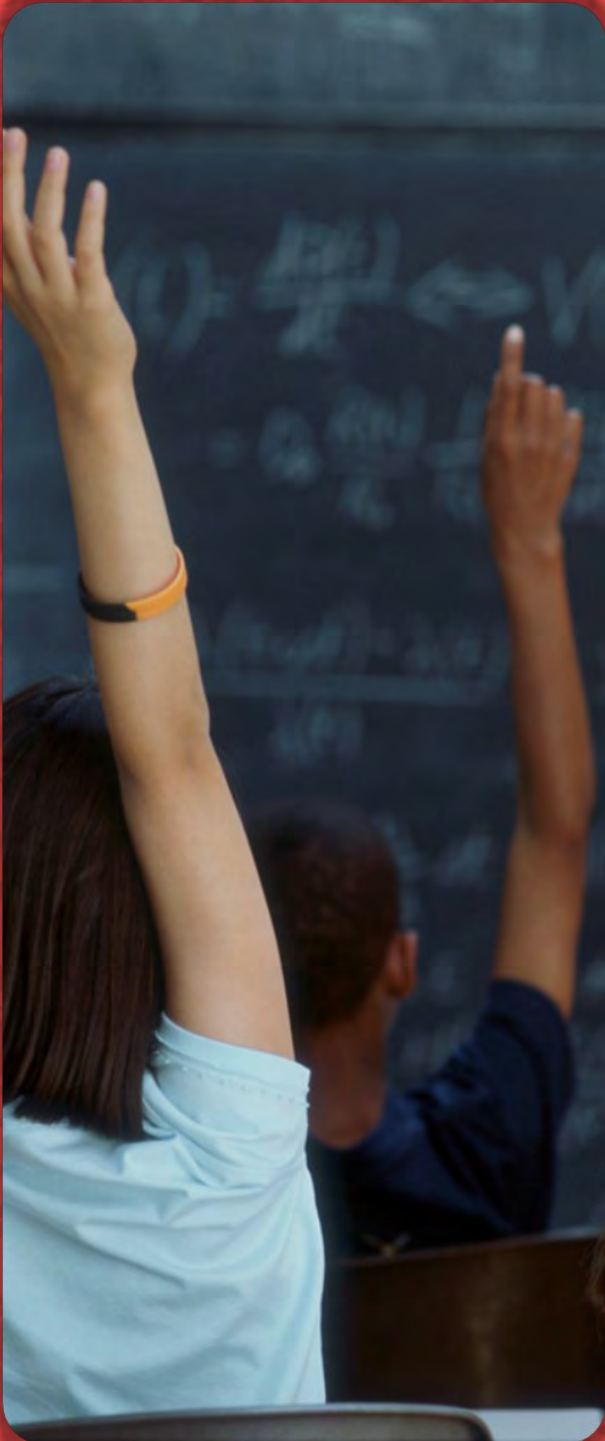
Due to time constraints, it may not always be possible to come up with questions ahead of time or ask questions after the presentation. Consider asking the speaker if he/she would be willing to review follow up questions. If so,

the site CAB Leadership or Liaisons can contact the speaker after the meeting with follow-up questions. The CAB may then review the answers to their questions during the next site CAB meeting.

It's always helpful to be specific! Guest speakers may feel more comfortable presenting on a topic when they know more about what the CAB intends to get from the presentation. Before deciding on a topic, ask the CAB to come up with specific questions or objectives. This may help guest speakers use their presentation time wisely and accommodate the CAB's educational needs.

# MEETING CONTENT

## Module 4



It's as important for the guest speaker to know the CAB as it is for the CAB to know the guest speaker! Consider creating a one-page (more or less) description of the CAB to give to guest speakers. This will help the guest speaker better understand the CAB's needs. It may also be possible to ask CAB Leadership or Liaisons to describe the CAB over the phone or email. Ask CAB members to work together to come up with a CAB description and/or mission statement to share with the guest speaker ([see page 11 for more information on CAB mission statements](#)).

It may also be helpful to come up with guidelines for guest speakers. There may be related topics that the CAB does not want the guest speaker to talk about. Since confidentiality during CAB meetings is very important, consider developing a confidentiality agreement for guest speakers to sign. This may help CAB members feel more comfortable welcoming guest speakers to meetings ([page 35 for more information on confidentiality agreements](#)).

# MEETING CONTENT

## Module 4



### Presentations by Conference Call

It may not always be possible for guest speakers to attend site CAB meetings. One site CAB recommends inviting guest speakers to present a topic over the phone or video conference. Imagine how many more guest speakers could attend site CAB meetings if held one of these ways!

Keep in mind there are challenges to not having a guest speaker physically in the room. It is important that the CAB has some material to reference during the presentation if they aren't able to see the presenter. It may be difficult to keep the CAB engaged in the discussion if they have no visual reference point. Request that the speaker provide a PowerPoint presentation or handout. Be sure to check with site staff about conferencing options.

### Minutes

Many site CAB find it helpful to take minutes or detailed notes during meetings. Talk to site CAB members about their preferences for minutes. There are pros and cons to taking meeting minutes. Minutes are a helpful reference for CAB members to review what happened during previous meetings. It also helps the CAB keep track of what topics have been covered. If the CAB would prefer not to take minutes, use copies of past agendas to track what topics have been covered.

Please note that there are many options for minutes. CAB members may feel more comfortable if minutes were only taken during some parts of the meeting.



# MEETING CONTENT

## Module 4

CAB members may request that other parts of the meeting such as personal story time or support sessions be left out of the minutes. CAB members may also feel more comfortable leaving names out of minutes. Due to confidentiality concerns, some site CAB members may not ever want to have minutes or notes taken. Minute taking may be a burden for CAB members. If the CAB is interested in taking meeting minutes, ask for volunteers. If there are no volunteers, consider asking the CAB Liaison to take minutes. Since minute taking can be an important task, it may help interest members to propose that the person taking the minutes be part of CAB Leadership as a Secretary or other similar role.

### Activities Outside of CAB Meetings

Many CAB members have stressed the importance of CABs participating in activities outside of CAB meetings when the gathering isn't specifically focused on HIV. Outside activities may help the CAB bond, may act as incentives, and may help the CAB maintain a balance of work and fun. Activities outside of meetings may take the place of meetings or take place at a separate time. Below is a list of possible activities:

- Fitness classes;
- Holiday parties;
- Attending other CAB meetings;
- AIDS Walks;
- Going to the movies;
- Participating in local health fairs;
- Bowling;
- Going out for a meal together; and
- Museum trips.

**“Being a part of the CAB  
makes me feel like I am helping  
the cause.”**

**- CAB Member**

# HEALTH EDUCATION

## Module 5

### Health Education at Site CAB Meetings

Many site CABs spend a great deal of time reviewing health education materials during site CAB meetings. Common health education topics include (but are not limited to):

- Clinical research;
- HIV/AIDS research and news;
- Substance use and HIV;
- Parenting and HIV;
- Safe sex practices;
- Living healthy with HIV;
- Healthcare;
- Scholarships; and
- HIV/AIDS 101.



[See page 51 for general site CAB meeting topic suggestions.](#)

### Time Spent on Health Education during Site CAB Meetings

Most site CABs review health education materials at every meeting, but some CABs choose to feature health education topics just a few times a year. The amount of time spent reviewing health education resources depends on the needs of the group and the site CAB's overall meeting goals. Several site CABs try to spend approximately 10-15 minutes of the meeting reviewing health educational materials.

# HEALTH EDUCATION

## Module 5

One site CAB varies the amount of time spent on health education materials based on the specific topic. If a topic cannot be completely reviewed during the meeting, then the topic review is continued at the next CAB meeting. Talk to your site's CAB members about their preferences for time spent reviewing health education materials.

Think about how to pick health education topics for site CAB meetings. It may be helpful to have a pool of topics to choose from. Some topics may be addressed when a relevant news article or research summary about the topic has been released. One site CAB picks topics for all of the next year's meetings during their December meeting. Consider asking site CAB members to volunteer topics during a meeting. Let CAB members know ahead of time that you will be brainstorming health education topics for future meetings so they can prepare and collect their thoughts and ideas.

Another way to brainstorm health education topics for future meetings is to keep a suggestion box available during meetings. Allow five minutes at the end of the meeting for CAB members to reflect on what they've learned and suggest topics for future meetings.

Keep in mind that some CABs discuss health education topics in a less structured way (for instance, relevant issues come up throughout the year that were not previously planned for a future CAB meeting). There may be news articles, press releases, and/or research summaries of interest that are released throughout the year. Consider asking CAB Leadership or the CAB Liaison to look out for health education developments ([see page 45 for more information on HIV/AIDS news and events for site CAB meetings](#)).

# HEALTH EDUCATION

## Module 5

### Types of Health Education Information

There are many different ways to review health education topics. Site CABs review the following types of resources when they discuss health education topics:

- Presentations
- Website links
- Books
- Press releases
- Magazines
- Local and national HIV publications
- Study websites
- Study-wide CAB conference calls.

Most site CAB members have stated that they are most engaged when learning from a presentation and/or guest speaker. Presentations are very helpful for reviewing health education topics because they keep the CAB engaged both visually and through listening.

Since not all CAB members may review written material at the same reading level, it can be helpful to consider presenting material in a PowerPoint or similar visual presentation to accommodate all members. This may also be something to consider when distributing materials to read before a presentation.

One site suggests using a variety of media to connect CAB members with health education resources. This site suggests reviewing research study websites and training materials, relevant news articles, new studies, and YouTube video clips about current news and research-related topics. The site recommends spending no longer than 40 minutes reviewing health education resources at one time, as interest fades over longer lengths of time. Talk with site CAB members about their preferences for time spent reviewing health education materials, and preferences for types of information.

# HEALTH EDUCATION

## Module 5



Some study websites, like the PHACS website, provide helpful information about general and study-specific research. The public PHACS website provides users with health education and study-specific information and resources. PHACS Researchers and CAB members can create their own account and have access to more information behind the login.

You may visit the public PHACS website, or create an account if you are a PHACS CAB member at: <http://phacsstudy.org>. *Note for PHACS CAB members: Another way to discuss health education and research summaries will be to use the brand new website discussion forum!*

Many site CABs feature updates from representatives who serve on study-wide (i.e., PHACS or IMPAACT) CABs during site CAB meetings. In addition to general updates, consider asking study-wide CAB representatives to review the most recent study-wide CAB conference call agenda. Study-wide CAB call topics might spark ideas for health educational topics to review during future site CAB meetings.

# HEALTH EDUCATION

## Module 5

### Research Summaries

Research summaries, also called “participant summaries” or “lay summaries,” are short articles that outline study findings. These summaries are typically written in plain language for non-medical professionals. In research studies, these summaries are often written for and distributed to study participants and their families. Research summaries are typically distributed at the same time as the release of a published study paper or abstract.



Research summaries can be helpful tools for site CABs. They are typically one page in length and describe the study purpose, population, what was done, and results. Reviewing research summaries during CAB meetings can be a helpful way for a site CAB to learn about recently published studies.

Most site CAB members receive research summaries and related materials during site CAB meetings. Other CAB members receive summaries by email and even by regular mail. However, keep in mind that not all CAB members may feel comfortable receiving research summaries or any study-related or HIV-related materials at home. Check with CAB members about preferences for receiving research summaries.

Since many CAB members indicate that they prefer to review health education materials and resources in presentations during CAB meetings, consider asking CAB Liaisons, CAB Leadership, and/or study staff to present participant summaries to the CAB.

# HEALTH EDUCATION

## Module 5

Many site CABs recommend inviting the site's Principal Investigator (PI) or Co-Investigator (Co-PI) to present a research summary during a site CAB meeting. Consider asking the PI or Co-PI to present the summary and allow time for questions and discussion. Many sites find that these kinds of discussions are an effective and timely way to share study results.

Just like it may be helpful to provide read-ahead materials of presentations by other guest speakers, also consider asking the site CAB to review research summaries ahead of time. This will allow CAB members to organize questions ahead of time. CAB members can bring their questions to the site CAB meeting and present them to the Principal Investigator.

### CAB Member Checklist: Guest Speaker Presentations

- Comments
- Questions
- Contact Information

In many cases, it takes time for people to process information, especially complicated medical research. When scheduling a research summary presenter, consider asking if they are willing to be contacted after the presentation to respond to additional questions/comments. CAB members may benefit from being able to submit questions or comments to the presenter after the presentation. It may be more efficient to select one person to contact the guest speaker with questions/comments. This person can forward CAB members' questions and/or comments to the guest speaker by email, phone, or mail, and share the feedback with the CAB during the next meeting.

# HEALTH EDUCATION

## Module 5



It may not always be possible to schedule a guest speaker to present a research summary. One alternative is to consider asking your study-wide CAB representative to take notes during a study-wide CAB presentation on a research summary, or to review the meeting minutes. Many study-wide CABs, like the PHACS CAB, review new research summaries during conference calls. Oftentimes, the author presents the summary to the CAB, and participates in a Q&A session following the presentation. The CAB representative can bring their notes, guest speaker presentation from the study-wide CAB call, and/or study-wide CAB minutes to a site CAB meeting. The site CAB can discuss the summary and notes together and compile a list of questions for the site CAB representative to bring to the study-wide CAB Liaison.

In many study-wide CABs, like the PHACS CAB, the study-wide CAB Liaison may be able to contact the presenter/author with questions, or connect the CAB with the presenter/author directly. It may also be a good idea to invite a site staff member to the meeting to clarify any immediate questions or misunderstandings.



# HEALTH EDUCATION

## Module 5

Another suggestion is to have the site CAB review the research summary before it is presented during the study-wide CAB call. This allows the site CAB representative to bring questions and feedback from their site CAB on the study-wide CAB conference call. Talk to CAB members about their preferences for reviewing research summaries and study-wide CAB conference call presentations.

As mentioned before, some site CAB members may not feel comfortable receiving research summaries or any study-related material at home, via email, or on their mobile devices. In an effort to accommodate all CAB members' preferences for receiving research summaries, one site creates binders for each CAB member that contain all research summaries. These binders are kept at the site and reviewed during site CAB meetings. Be sure to consider confidentiality and privacy rules and regulations when working closely with your site staff and/or CAB members.

One site suggests keeping a booklet or binder at the clinic site that contains all research summaries and press releases. The booklet can be shared with families interested in joining the CAB and learning about new studies.

Another site posts research summaries on a bulletin board that is displayed somewhere in the clinic. This allows site CAB members and potential CAB members to review summaries at their own pace. However, some sites report that this strategy has been relatively unsuccessful since no one looks at the bulletin board. When taking this approach to show information, please make sure you have permission from your site leaders, CAB leaders, and fellow CAB members. Some sites do not post any research-related information. Some sites post contact information for a site staff or CAB member who is willing to answer any questions about research-related materials.

# CLOSING REMARKS

**“I participate in the CAB to help the community, give input [for research studies], be a voice, and make a difference.”**  
**-PHACS CAB Member**



Community advocacy can take many forms, and in some cases, starts at the site Community Advisory Board (CAB) level. Studies like the Pediatric HIV/AIDS Cohort Study (PHACS) have many clinical sites all across the United States and Puerto Rico. International studies have clinical sites all around the world! It is vital that all clinical sites establish a site CAB that can accurately reflect the interests of their unique and empowered communities. Clinical Investigators rely on CABs to give feedback about research in order to improve and optimize clinical research studies for the children and families who are most affected by them.

We hope that the CAB Handbook will be used as a tool to help create new site CABs at sites without current community representation, and a resource to nourish established, flourishing CABs across all clinical sites. So help the community. Give input and feedback about the studies that affect your children and families. Be a voice for the community, and make a difference in the lives of those affected by clinical research studies.

*Please send all questions and comments about the CAB Handbook to Megan Lukschander ([MeganLukschander@westat.com](mailto:MeganLukschander@westat.com)).*

## Appendix I

Instructions: Allow ten minutes for CAB members to visit with each other and find one person to match each of the characteristics below. Once one person's list is complete, or ten minutes are up, ask CAB members to share something interesting they learned about someone else.

Home is more than an hour away from the clinic	Is left-handed	Speaks another language	Has a daughter in PHACS
Lives in their birth state	Has been on the PHACS website	Has been in more than one research study	Has not been to a PHACS Network Meeting before
Goes to CAB meetings regularly	Likes to watch sports	Knows what PHACS stands for (quiz them!)	Has been to the doctor this month
Has more than one child	Is involved in more than one community group/organization	Has a son in PHACS	Likes spicy food

## Appendix II

*Insert CAB name*

Insert CAB Address

### **Community Advisory Board Member Contract**

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**Member Role:** Pediatrics CAB (PCAB) members will play an important role in ongoing studies.

- Members will be available to communicate with other individuals considering or currently involved in research studies.
- Members will review informed consents and provide their perspective as needed.
- Members will provide community perspective on new studies and provide feedback on ongoing studies.
- Members will be available to participate in research network activities as local CAB representatives and receive clinical trial training.

**Peds ID Staff Role:**

- Staff members will provide training in clinical research and other topics.
- Staff members will provide stipends and MetroCards on the date of each meeting.

- 
- Monthly PCAB meetings will be the third Wednesday of each month from 11:00am to 12:30pm. Any problems with this date and time will be brought to the attention of the group and discussed.
  - Generally, no family members or friends should attend the monthly meetings. However, if a member has a childcare situation, they should let the research staff know ahead of time and the staff will help find a solution.
  - Each CAB member will receive a \$25 stipend, lunch and a MetroCard for attendance at the monthly meetings.
  - If a member misses more than 3 monthly meetings within a 6 month period, they will be asked to step down from their role as a CAB member. Exceptions can be made for emergencies as approved by the CAB membership.
  - For courtesy to other members, research staff and CAB members should try to be on time to monthly meetings. If you will be more than 15 minutes late, please call to let the CAB know.
  - Confidentiality is extremely important. Any personal information shared at the meetings stays within the group.
  - Members should respect fellow CAB members and not interrupt when another member is speaking.
  - Phones should be put on vibrate during monthly meetings.

I have read the above member contract requirements and agree.

---

Member Signature

---

Name (Please Print)

---

Date

---

Address

---

Phone Number(s)

## **Appendix III**

*Insert CAB name*  
Insert CAB address

### **Community Advisory Board Visitor Contract**

We would like to welcome you to the Pediatric ID Community Advisory Board meeting. Before joining the meeting, please read over the following guidelines for visiting guests. We aim to maintain a safe and interactive environment that encourages discussion and learning. We request that guests adhere to similar guidelines that members are required to maintain.

Confidentiality and individual privacy are extremely important to us. Any personal information shared by members or guests at the meetings must remain within the confines of the meeting.

Visitors and members are not required to share personal information related to HIV. If HIV information is shared, it is especially important to keep this information within this group only.

Visitors should respect CAB members and staff. Interrupting while another is speaking is not allowed. Negative comments or put downs are not allowed.

We ask that you put your phone on vibrate during the meeting so that we can minimize interruptions.

I have read the above visitor contract requirements and agree to these guidelines during my participation.

---

Visitor Name

Visitor Signature

Date

## Appendix IV

### CAB Meeting Checklist

*Submitted by: Theresa Aldape, LMSW, Baylor College of Medicine/Texas Children's Hospital*

- o Order food for the meeting
- o Mail out CAB letters
- o Send out emails to CAB members
- o Call CAB members
- o Update agenda
- o Download information/lay summaries/new protocols to review and have it available for each CAB member at the meeting (*This information can be e-mailed to members who could not attend the meeting*).
- o Consider and check with members who may want to be on a conference call during the CAB meeting due to their work, home or school schedule
- o Make sure the CAB folder contains the following:
  - o Prepared agenda
  - o Sign-in sheet
  - o Copy of CAB letters
  - o Minutes
- o Send out a reminder email to all CAB members
- o Obtain parking stickers
- o Complete compensation forms for CAB members
- o Provide travel expenses
- o Prepare raffle items/giveaways
- o Consider a theme/event/celebration (*holiday, fall, valentine's day, Mardi Gras, St. Patrick's day, celebrate CAB achievements day, etc.*)