

# 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.

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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).

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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.

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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.

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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).



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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.

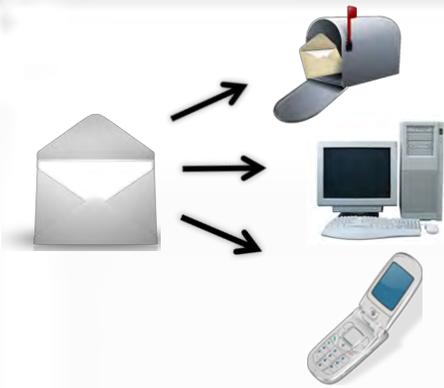
One of the CAB's missions is to provide community feedback about research studies in order to optimize them for the participants and families who are most affected by them. Therefore, it is important that CAB members feel that their opinions are being heard. Talk to site staff and CAB members about the most appropriate way to provide feedback (see Module 2 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).



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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.