PHACS CAB

FEEDBACK FOR RESEARCHERS

We asked the CAB about their feedback for PHACS researchers, and they identified diversity and retention as priorities. Similarly to last year, the CAB encourages the PHACS research team to continue to reach out to participants, with considerations for disclosure, familiarity/non-familiarity with research, mental health, language barriers, and family issues.

What feedback do you have for researchers?

- Reach participants on their level—know that some participants may not feel comfortable taking home materials with "HIV" language if they have chosen not to disclose to their families. Posters and magazines in a clinic related to HIV may also be a deterrent to some families.
- Utilize your community liaisons. Many sites have case workers, peer navigators, social workers, and other community representatives who have access to community resources. If site staff are unsure of what resources in the community are available to participants, they should consult their in-house community liaisons.
- Consider hiring a Peer Educator to establish a personal connection with participants. They can also be tasked with keeping track of participants throughout the year in between study visits.
- Consider translation services at the meetings so you can get feedback and opinions from speakers of languages other than English.
- As a researcher, how valuable is it to you to have diversity among the participants that assist you with studies? What helps you stay connected to the HIV community at your site?
- Ask the families if there is anything that would make them feel more comfortable during visits. Being open to feedback throughout study visit and after.
- To me, the best way to reach out to families is to constantly remind them about how important the data in the research will be, not only for themselves, but for future generations to come until there is a cure.

What questions do you have for the PHACS community?

Please contact Megan Reznick (MeganReznick@westat.com) with questions and comments.