

This year, the PHACS CAB reevaluated the purpose of the Community Concerns and Priorities List. We asked the CAB about their goals for the future of PHACS, and they identified recruitment and retention as priorities. Below is the CAB's feedback regarding successful recruitment and retention strategies for participants in PHACS. By sharing their own reasons for participating in research, the CAB hopes to assist the PHACS research team in reaching out to families affected by HIV. Please share with your local sites, and send feedback to Megan Reznick (MeganReznick@westat.com).

Why does your family participate in research?

- To give back to researchers.
- To find a cure.
- I gladly participate because if someone years ago would not have participated in research, the strides and discoveries that led to where I am today would have never been made. This has not only allowed me to live a full and long life, but it has also helped me deliver an HIV-negative child, who is thriving now in life.
- I participate in research to help make a difference. I try to improve the lives of others, especially ever since losing someone to this disease.
- I participate to advance science and help others have a better quality of life.
- To help others learn about health outcomes. It seems like community service to me.

Why has made you not want to participate in research?

- Time
- Feeling like "nothing more than a number."
- Difficulty qualifying for studies.
- Having a limiting illness keeping me from being able to go to the clinic in person.
- Moving away from the clinic.

What advice do you have for researchers on how to reach out to families?

- Be compassionate with what the participant may be feeling or experiencing. Sometimes, participants are very stressed and just need help putting their feelings together. Be an ear to listen, and encourage them by suggesting additional resources and/or making appointments with medical providers or case management officers, if available.
- I am dealing with HIV, and with it comes anxiety. When I have participated, I have had a Study Coordinator, who was approachable friendly. This helped me feel like I was not just a number to them. They really educated me and made me want to participate. Reach out to participants to make them feel like site staff are approachable and caring.
- 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.
- Facilitate travel, parking.
- Consider giving them other incentives.
- Consider using lay language, especially for those who may not comprehend.
- Explain clearly that study participation is voluntary.
- Give participants contact information for follow up questions throughout their participation.
- Continue treating and providing care to the patient with respect and care.
- Sometimes they may not enroll the current child, but then decide to enroll the next baby born.
- Be prepared to go the extra mile.
- 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.

Where do you see the future of PHACS?

- I want to see PHACS become much more recognized so that others know about it and want to become more involved. I would like to see PHACS also target other groups/populations, and possibly reach out to people around the world.
- I hope PHACS can continue sharing their research to prove why it is so important to continue research in this population.
- I see the future as evolving. In the beginning, the face of HIV and AIDS was totally different to the face of HIV and AIDS today. My true goal is that anyone living with the disease will never experience any type of stigma from any health care provider, any clergyman, or any human being off the street. But, the ultimate goal is a total cure, not just a vaccine.
- I want for more women, children, and families to join PHACS not only for the financial gain, but for the education and knowledge that may help them in the long run.

- I want to provide the community and researchers with experiences we have shared through PHACS and with community. My goal is to continue to gain and share the knowledge I have learned throughout the years from PHACS.
- I want to open up more studies for affected children of mothers who took medication while pregnant. I want to focus on other related medical concerns.
- I would love participants in PHACS to be involved in HIV cure research.
- My desire is to learn more, and ultimately get more people involved, not only in PHACS, but in HIV research.

What other advice would you like to share with PHACS researchers?

- Consider reaching out on social media to show the results of some of these important studies.
- Occasionally at study visits, consider asking participants about what has given them research fatigue. This can help identify common problem areas that you may be able to address with other participants before they fall out of care.
- Share study results at study visits. While the family is waiting, show them research summaries, or the PHACS website to show them everything that the study is doing.
- Find ways to maintain contact with families throughout the year, such as birthday or holiday cards, invitations to community meetings or support groups, or friendly texts.
- Don't lose sight of compassion when dealing with participants. Be resourceful at your sites and keep up the great work you are all doing.
- The only advice I can give is to remember that when you see a patient, they are not just a person who is HIV-positive; they are a living being with a bleeding and beating heart, in other words, a human being.
- Consider translation services at the meetings so you can get feedback and opinions from speakers of languages other than English.
- Never stop looking for ways to involve the community.
- 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.

What questions do you have for the PHACS community about recruitment and retention?

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