

**CAB Conference Call
October 31, 2024
12:00 ET
Meeting Minutes**

Participants:

Alex	FSTRF
Andrea	Jacobi Medical Center
Antoinette	University of Miami
Chitara	Ann & Robert H. Lurie Children’s Hospital
Claire	Harvard T.H. Chan School of Public Health
Eduardo	Harvard T.H. Chan School of Public Health
Ellen	Ann & Robert H. Lurie Children’s Hospital
Falon	University of Colorado, Denver
Gena	University of Miami, Florida
Jennifer	Ann & Robert H. Lurie Children's Hospital of Chicago
Joy	Westat
Karim	Westat
Kim	Texas Children’s Hospital
Kylie	Texas Children’s Hospital
Liam	FSTRF
Liz	Harvard T.H. Chan School of Public Health
Lynn	Northwestern University
Mandy	Harvard T.H. Chan School of Public Health
Paige	Harvard T.H. Chan School of Public Health
Raiko	University of Colorado, Denver
Rosalva	UCSD
Tameka	St. Jude Children Research Hospital

- **APPROVAL OF MINUTES**

The minutes from the September call were approved with no changes.

- **NEXT PHACS GRANT CYCLE UPDATES + CONVERSATION WITH PHACS MPIS (ELLEN CHADWICK, PAIGE WILLIAMS, JENNIFER JAO, LYNN YEE)**

Claire introduced the PHACS multiple Principal Investigators (mPIs) (Paige, Ellen, Jennifer and Lynn) to the CAB members. She explained that a new Request for funding (RFA) was sent by the National Institutes of Health (NIH). This new RFA is a recompetete, so Harvard is not guaranteed funding for PHACS. In addition, the budget in the RFA is significantly smaller. A small budget means that the PHACS network will change, including a smaller number of clinical sites. The mPIs will share their thoughts on what will be included in the application regarding community engagement. It is important to note that in the new grant, Paige, Jennifer and Lynn will be the new PHACS mPIs.

Paige mentioned that the community engagement in PHACS has no equal in other networks. The idea is to continue a similar model. NIH decided to change research priorities to focus on adults living with HIV, instead of the pediatric population and people exposed to HIV, but uninfected. With the NIH decision in changing the research priorities, the PHACS studies (SMARTT, TERBO, AMP Up and AMP Up Lite) need to close by the end of July. The mPIs are proposing a single protocol that enrolls participants and follows them over time. The model of community engagement proposed includes one Community Advisory

Board (CAB) and several paid Task Force members. The paid Task Force members will continue to review the science and give input and refine the goals of the protocol. The new application includes seven sites. The mPIs are proposing that the new CAB includes participants from those sites, like the HOPE CAB.

Paige explained the proposed protocol:

- RISE: **R**esearch on **I**mmune Aging, **S**exual and Reproductive Health, and Perinatal Acquisition: **E**lucidating Relationships in HIV
- Focuses on reproductive health, effects on taking medications for a long time, biological aging, chronic stress of living with HIV. Understanding how HIV and antiretroviral treatments affect aging and sexual and reproductive health. Other topics to be addressed include menopausal symptoms and ovarian health.
- Different groups of participants: Men with Perinatal HIV, Women with Perinatal and Non-Perinatal HIV (including pregnant and non-pregnant participants).
- The overall infrastructure of RISE focuses on the bidirectional input between participants and the protocol team. Participants will shape the important scientific issues that the protocol will be going to address.

Ellen mentioned that HOPE participants will have the opportunity to join this new protocol after they finish the HOPE study.

Questions from the CAB members:

Tameka asked what the CAB role in this new protocol is.

- **Paige** answered that the CAB role will be similar. The CAB will have monthly meetings to share information about the development of the protocol and getting feedback from community members. In the first year, the community members will provide input on the surveys and the protocol design. Once the protocol opens and is enrolling participants, the CAB will provide feedback on study visits. In addition, the CAB will have an essential role in sharing the research findings.
- Several resources that the CAB provided their feedback will continue to be used: geocoding materials and microbiome brochure.

Rosalva asked several questions:

- Which sites will be included in the application?
 - **Paige** shared that the sites included in the application are:
 - Baylor College of Medicine
 - Jacobi Medical Center
 - St. Jude Children’s Research Hospital
 - SUNY Downstate Medical Center
 - University of Miami
 - Ann & Robert H. Lurie Children’s Hospital of Chicago
 - Children’s National Medical Center (New site)

- Do CAB members from sites not included in the application will be able to participate in the new CAB?
 - **Paige** stated that leadership is still exploring the possibility of current CAB members from sites that were not selected to participate in the new CAB.
- Is leadership considering representation of other ethnicities in the new CAB, especially the Latino population?
 - **Paige** noted that the sites were selected based on having a large number of participants to enroll and being in an area of high HIV incidence.
 - Some of the sites that were included have a very high percentage of Spanish speaking participants.

Kim asked if participants that live several hours away from the clinical site will be allowed to participate in the study.

- **Paige** indicated it is up to the participant if they want to travel. She explained that the study will only have an entry visit, and one follow up visit consisting of a survey. The population that will be enrolled includes adults living with HIV. In addition, the new research will study women in pregnancy, and children born to women living in HIV (although the children will not be enrolled in the study).
- **Kim** shared that community members could reach out to possible participants to find out if they are interested in participating in the new study.
- Other questions that were addressed:
 - How the new CAB will be organized? Just one group?
 - Leadership is thinking about having a single CAB with around 16 members. Since the new study will focus on questions that relates to the three cohorts (Men with Perinatal HIV, Women with Perinatal and Non-Perinatal HIV), leadership is thinking of only having a single CAB. It is possible to have subgroups focusing on different topics.
 - In the new CAB, is there going to be a revised guidebook and goals?
 - It is likely that the guidebooks and goals will need revision.

Rosalva explained the importance of the Spanish CAB. She talked about the difficulty for the Latino community to navigate the health system in the US. In addition, the Spanish CAB was a safe place where community members could share their thoughts and provide feedback in their own language. She hoped that, in the future, this decision could be reconsidered.

- **Eduardo**, as one of the Spanish CAB liaisons, emphasized the good news that the Spanish CAB was able to have a year of meetings thanks to the guidance of Claire and Mandy. Also, there is a possibility that Spanish speaking community members could participate in the next iteration of PHACS.

Chitara asked what downsizing a CAB looks like.

- **Jennifer** answered that leadership is thinking about having one or two representatives from each site. The idea is to integrate the participants of the new protocol into the CAB. Leadership has not decided how what the transition will look like.

Other questions from community members:

- What makes the current participants less valuable to the national CAB moving forward?
 - **Jennifer** indicated that current community members are not less valuable, and leadership needs their expertise. However, with a limited budget, it is important to be inclusive of the new participants.
- How does staffing will be affected?
 - Site staff that was not included in the application will not be working on PHACS. **Paige** explained that the budget of all entities (Harvard, Westat and FSTRF) was cut by 2/3.
 - **Jennifer** indicated that the commitment of leadership is to write the best grant that they can, to be able to continue the research. If the application in not funded, sites will not be able to continue with the research activities.

NOTE: The next CAB call will be on December 5, 2024, at 12:00 PM ET.