CAB Conference Call June 24, 2021 12:00 ET Meeting Minutes

Participants:

Claire Eduardo Exzavia Falon	Harvard T.H. Chan School of Public Health Harvard T.H. Chan School of Public Health Children's Diagnostic and Treatment Center University of Colorado, Denver
Joel	University of Puerto Rico
Julie H.	University of Alabama, Birmingham
Karim	Westat
Kimbrae	Texas Children's Hospital
Kylie	Texas Children's Hospital
Laurie	FSTRF
Liz	Harvard T.H. Chan School of Public Health
Mandy	Harvard T.H. Chan School of Public Health
Megan	Westat
Raiko	University of Colorado, Denver
Sannita	University of Miami
Tracy	Westat
Vanessa	Harvard T.H. Chan School of Public Health
Veronica	University of California, San Diego

• APPROVAL OF MINUTES

The minutes from the May 27, 2021 call were approved with no changes.

• CAB CHAIR ANNOUNCEMENT (2021 – 2023 TERM)

Megan thanked everyone for voting for the approval of **Kim** as Chair and **Exzavia** as Vice Chair. **Kim** and **Exzavia** thanked everyone for the support. CAB members congratulated both of them on their new role.

• FALL AND SPRING MEETINGS ANNOUNCEMENT

Fall 2021 Virtual, Spring In-Person and Attendance Requirement Update

Megan mentioned that the Fall 2021 Leadership meeting will be held virtually on October 26-27 2021. The in-person Network Meeting and CAB Retreat will be rescheduled for Spring 2022, around May. **Megan** mentioned that CAB members need to attend 70% of the CAB calls between January 2021 and February 2022. Attendance of at least 9 CAB calls is required to be eligible to be invited to the Network Meeting and CAB retreat. Members that attend the monthly calls have a unique perspective to share with research staff. It gives them the knowledge about what is going on PHACS and the CAB. They can share feedback from the CAB and their local community. **Megan** mentioned that Leadership can make eligibility exemptions on a case-by-case basis. The invitations for the Network Meeting and CAB Retreat will be sent by March 2022.

Virtual CAB retreat

Claire asked the CAB members if they are interested in holding a Virtual CAB Retreat this Fall. The CAB members agreed to hold a Virtual CAB Retreat. Virtual CAB Retreat attendance is optional. **Veronica** asked if participants who cannot make the monthly calls could be invited to the Virtual CAB Retreat.

Megan mentioned that the focus of the Virtual CAB Retreat is to work together as CAB members. She said it is an opportunity to bring together people from different places and perspectives. **Kim** welcomed the idea of inviting other participants. She mentioned that they could become future CAB members. CAB members agreed to invite site CAB members to the Virtual CAB Retreat. The CAB will start planning for the retreat during the August CAB call. **Megan** will send an email asking for anyone interested in participating with the Retreat Planning Task Force.

• HECC UPDATE & CAB FEEDBACK

Megan introduced **Vanessa Vassall. Vanessa** is the new HOPE (Health Outcomes around Pregnancy and Exposure to HIV/ARV) project manager. **Vanessa** mentioned she was excited to work with the HECC and CAB. She said that the HOPE study explores the health and well-being of women living with HIV over time. **Vanessa** reviewed the following eligibility criteria for HOPE:

- Women living with HIV
- Ages 18 and 40 years old
- 30 and under who have not had children
- 40 and under who are pregnant or recently gave birth
- 40 and under who are not pregnant
- Postpartum

Vanessa mentioned that HOPE will recruit participants from other studies, such as SMARTT. **Kim** asked about the HOPE age eligibility requirement. In addition, she asked for a list of participating sites. **Vanessa** explained that these are the eligibility criteria written into the protocol at this time. **Vanessa** mentioned that 12 sites will participate in HOPE. **Liz** added that the protocol team talked a lot about the age eligibility. She explained that it was centered around childbearing age. **Kim** wondered if the age range could be extended in the future. **Liz** answered that there is a possibility that future substudies will be funded with additional age ranges.

Vanessa asked CAB members for their feedback about recruitment strategies. She asked about challenges for recruiting women with kids. Feedback from the CAB included:

- **Veronica** suggested not to talk about women who have not "yet" had children. Many women don't feel that motherhood is the path for them. Also, some women will not be able to experience motherhood. **Liz** agreed to be cautious with language used such as "women of reproductive age" or "childbearing age."
- **Kim** suggested maintaining good relationships with local clinics. The study team could recruit women when they are seeking medical treatment.

Claire asked what type of information a first time participant needs to know before deciding to be part of the study. Feedback from the CAB included:

- **Kim** answered that women need to feel comfortable and safe. The participant needs to know that the study team will help her if she needs any healthcare follow up. **Kim** mentioned that participants join a study because they feel safe. Also, they know the study results could change history and make a better world for everyone.
- **Sannita** agreed that women need to feel comfortable and safe.
 - $_{\odot}$ $\,$ Site staff should consider inviting them to lunch. Have one-on-one contact.
 - \circ $\;$ Emphasize the purpose and benefits of the study. Explain how the study can help them and others.

- **Claire** talked about putting emphasis on the results of the study. It may also help to explain how the study can help other families and people born with HIV.
- **Shary** mentioned that it is important to sit down with participants to hear their experiences. It can be helpful to explain that the purpose of the study is to help other affected by HIV.
- **Exzavia** agreed that sharing experiences is the best way to promote the study.
- **Claire** talked about the panel "Hopes for HOPE" led by Kim at the last PHACS meeting. The panel consisted of people with different roles in PHACS. Panelists shared what were their hopes for the study. They also shared their experiences participating in other studies.
- **Kim** expressed the importance that study participants have a support group. It is important to be around people that share similar life experiences as them.
- **Shary** mentioned that support can come from site staff like case managers. Study team need to be mindful how to present the study. She reminded researchers of the following:
 - Be compassionate
 - Emphasize on the benefits of the study
- Liz mentioned that it's important to use participant-centered and compassionate stance in all of our work.

NOTE: The next CAB call will be on Thursday, July 22, 2021 at 12:00 pm ET.