

**CAB Conference Call
November 30, 2023
12:00 ET
Meeting Minutes**

Participants:

Andrea	Jacobi Medical Center
Anisa	Harvard T.H. Chan School of Public Health
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
Falon	University of Colorado, Denver
Gena	University of Miami, Florida
Jackie	Westat
John	FSTRF
Juan	University of Miami
Karim	Westat
Kim	Texas Children’s Hospital
Kylie	Texas Children’s Hospital
Liz	Harvard T.H. Chan School of Public Health
Mandy	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 October call were approved with no changes.

• **ICEBREAKER**

Mandy led the icebreaker.

• **SELF-CARE SPACE**

Eduardo led the self-care space.

• **UPDATES: NATIONAL CAB CALL POLICIES**

Mandy explained the new national CAB policy. She mentioned that participants who attend national community group calls will receive compensation through Westat. Participants that attended the October and November calls will receive a \$25 Amazon gift codes via email. The new policy includes that the Zoom link will only be sent to current CAB members and site staff.

Claire said that this new policy is an opportunity to recruit new members and have representation of every site. In addition, the remuneration is a way to thank every CAB member for their time and effort.

- **BRAINSTORM: NIH SCIENTIFIC AIMS**

Mandy explained that the NIH is requesting information on gaps and priorities related to HIV and women. They are requesting that the community provide their experiences and opinions about topics that are most important in research. **Mandy** explained that they want to gather input from the PHACS community members to submit to NIH. A survey will be sent by email to all community members to gather additional feedback.

CAB member feedback:

- **Kim** mentioned there is need for research on women with HIV over the age of 40. Research involving the effects of the medications on their body, especially the first HIV medications.
 - **Chitara** added that research focusing on the trauma to the body that the HIV medication causes, especially trauma to the pelvic floor, is needed.
 - **Liz** agreed that pelvic floor issues are not discussed enough.
 - **Claire** said that these issues aren't spoken about, and they could be very common.
 - **Kimbrae** shared that research on fibroids and genetics are needed as well.
 - **Tameka** mentioned that young ladies are getting the help they need early. There are many studies focused on younger women. However, there is a need for research on older women. There are several questions that haven't been answered, such as why women are living longer with the virus.
She added that researchers and health care providers should understand that HIV is different for everyone. They should do research in every stage of women's lives, not categorizing women by their age group.
- **Rosalva** mentioned a women's conference that will be held in San Diego in February 2024. The topic of the conference includes HIV research in women and children. After the conference, she will share with Mandy all the information that was shared during the conference.
- **Gena** suggested research on breast and anal cancers, especially in children born with HIV.
- **Rosalva** talked about the importance of mental health. There are great findings in HIV research, but there are still issues related to mental health and stigma. She explained that there has been no improvement in terms of openly talking about HIV diagnosis because of fear of discrimination and stigma. She suggested studies involving how women feel about their diagnosis, and how they disclose to families and friends.
- **Kim** mentioned that peer counseling is an excellent way to reach out to women. She indicated that staff and counselors would never completely understand what the woman is going through. She suggested implementing peer counseling from the youth to older adults. It is a way support woman and make sure they are healthy and happy.
 - **Claire** added that Kate Powis shared a research opportunity about mental health interventions, specifically social connectedness, and resilience.

Barriers to meeting some of your goals that are related to living with HIV:

- **Kim** indicated that copayments are a barrier. The cost of some medical services and medications have increased to a point that people are not able to afford them.
- **Chitara** mentioned several barriers:
 - Lack of HIV education of clinical staff. They need to be more empathetic with the patients and acknowledge them as humans. It is important that they understand and respect why a patient would not want to disclose their HIV diagnosis.
 - **Gena** agreed providers need more education about HIV.
 - There is a need for sexual health education at schools.
 - A barrier to getting the medical care needed for people that have a job is that clinics are not open on weekends. So, people need to take time off from work to go to their appointments.
- **Antoinette** indicated that a barrier to receiving services is health insurance. Health insurance doesn't cover all the services needed, including case management.
- **Tameka** pointed out criminalization of HIV. Some states require disclosure of HIV. However, for other STDs there is no requirement for disclosure. For women, even disclosing their HIV status to their partners could be a problem if the partner says it was not disclosed.
 - **Claire** mentioned it is important to advocate and promote changing of laws around criminalization of HIV.

NOTE: The next CAB call will be on January 25, 2024, at 12:00 PM ET.