

**CAB Conference Call  
January 26, 2017  
12:00 EST  
Meeting Minutes**

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**Participants:**

<b>Alexandria</b>	FSTRF
<b>Amy</b>	University of California, San Diego
<b>Andrea</b>	Jacobi Medical Center
<b>Claire</b>	Harvard University
<b>Deb</b>	Harvard University
<b>Delia</b>	University of Miami
<b>Exzavia</b>	Children's Diagnostic and Treatment Center
<b>Gina</b>	University of Miami
<b>Jeanie</b>	University Southern California
<b>Jennifer</b>	University of Colorado, Denver
<b>Joel</b>	University of Puerto Rico
<b>Julie</b>	University of Alabama, Birmingham
<b>Julie</b>	Westat
<b>Kate</b>	Harvard University
<b>Kimbrae</b>	Texas Children's Hospital
<b>Kylie</b>	Texas Children's Hospital
<b>Lesley</b>	Texas Children's Hospital
<b>Marilyn</b>	Bronx-Lebanon Hospital Center
<b>Megan</b>	Westat
<b>Raiko</b>	University of Colorado, Denver
<b>Rosetta</b>	Bronx-Lebanon Hospital Center
<b>Stephanie</b>	University of California, San Diego
<b>Stephanie</b>	University of Miami
<b>Theresa</b>	Texas Children's Hospital
<b>Veronica</b>	University of California, San Diego

- **APPROVAL OF MINUTES**

The minutes from the December 8, 2016 call were approved with no changes.

- **WOMEN'S COHORT**

**Deb Kacanek** talked about the Women's Cohort. PHACS is starting to look at creating a cohort of women who have HIV. The women's cohort may include women who are enrolling their babies into the SMARTT study. It also may include women who are in the AMP and AMP Up studies. PHACS has the opportunity to learn more about women. Researchers want to study women to be able to help make better guidelines for care for women living with HIV. The Women's Cohort would allow researchers to expand the research on women living with HIV that is already being done in PHACS.

The PHACS team is working to put together the Women's Cohort. There are not yet resources available to start the Women's Cohort. A small group of researchers from the Maternal Exposures Working Group (WG) and Complications WG are working to create the Women's Cohort. The group has been meeting since September 2016. The team wants to develop at least 3 concept sheets. These concept sheets would use data that has already been collected on women in PHACS. The concept sheets would hopefully be finished by March of next year. The first concept sheet will look at trends in antiretroviral (ARV) use in pregnancy.

Currently, the team is trying to come up with the research questions for the Women's Cohort. The team wants to know what the highest priority areas are in women's health for women living with HIV.

**Jennifer** asked about the concept sheets using data that have already been collected in PHACS. **Jennifer** wondered whether the team would need additional consent from participating mothers to use their data for new studies. **Deb** talked about informed consent for the Women's Cohort. Women will need to consent for any new studies. Consent is not required to use any of the data that has already been collected in PHACS. This is because women already consented for their data to be used in PHACS studies.

**Kate Powis** talked about the first concept sheet about ARV use in pregnancy. Researchers are interested in learning about women's adherence to the ARVs they were prescribed. This will help researchers learn if there are any difference across the country. This data has already been collected, and consent was already given by women participating in PHACS. Concept sheets like this will help researchers find out what additional research questions they should focus on.

**Stephanie** asked about whether researchers would be interested in finding out about medications taken before pregnancy. **Stephanie** wondered whether medications taken before pregnancy could have a later effect on pregnancy. It may be helpful to look at how long women took ARVs before pregnancy. **Deb** talked about women currently enrolled in PHACS. The Women's Cohort will be looking at data that has already been collected in PHACS. PHACS collects data about ARV use during or shortly before pregnancy. **Stephanie** talked about how many medications may be made for men's body types. It may be helpful to know how medications specifically affect a woman's body.

**Deb** and **Kate** reviewed the following questions and responses with the CAB:

**1. How important is it to you to do more research on women's health and the health of women with HIV within PHACS?**

**Kim** talked about the Women's Cohort. It is very important to study women in PHACS. Mothers may be responsible for health decisions for themselves and their children. Women may also be interested in learning about which medications are the safest.

**Jennifer** talked about the importance of studying women living with HIV. Medications may have a different effect on women's bodies. It may help women living with HIV now and in the future. It may help to improve care. It may also help women to find more affordable treatments.

**Lesley** talked about studying women in PHACS. It is important to study changes in women over time. It may be helpful to study women who have had many babies.

**Theresa** talked about connecting women living with HIV to resources. Many women in PHACS have an interest in helping others.

**Julie H.** talked about mental health in women living with HIV. It may be helpful to collect mental health information from women before and during pregnancy.

**2. What would be barriers we should keep in mind?**

**Theresa** talked about barriers. Transportation to clinics can be a barrier. It may also be hard for women to find childcare.

**Veronica** talked about barriers. Many mothers have not disclosed to their families. It may be difficult to collect data from mothers during visits where their children are there, too.

**3. What questions about women's health are most important to you? What questions do you think are most important for the PHACS team to work on?**

**Kim** talked about important questions about women's health. It would be helpful to know what long-term effects ARVs have on the reproductive system. It would also be helpful to learn about possible early menopause.

**Jeanie** talked about the long-term effects of ARVs on bone density. It may be helpful to look at how long women have been taking ARVs.

4. One of the challenges we face is that in SMARTT we do not have contact with women's health providers since we focus on the child's health. What information do you think would be important for us to learn from your doctors and ask them to provide?

**Jeanie** explained that many women may be willing to share all their information. Many women have benefited from past research studies. It may be helpful to get information about women's ARV use.

**Theresa** talked about women's health issues. It may be helpful to look at women's cancer history. Women may want to share information from annual pap smears.

**Kim** talked about women's health. It may be helpful to share information about mental health. Women may also want to share information from their gynecologists. Many women have had the same doctors for many years.

**Marilyn** talked about women's relationships with their doctors. Many women have good relationships with their doctors. This may help women feel more comfortable sharing their information with PHACS.

**Deb** talked about the future of the Women's Cohort. The Women's Cohort will review the CAB's feedback during their next conference call. The team wants to continue to seek feedback from the CAB during CAB conference calls. The team may also be interested in inviting CAB members to some Women's Cohort conference calls. CAB members may also have 1-on-1 calls with **Deb, Claire,** and/or **Megan** to talk about the women's cohort.

**• HEALTH EDUCATION AND COMMUNICATION COMMITTEE (HECC) UPDATE**

**Claire** talked about the HECC. The HECC is currently working on the PHACS films. **Claire** and **Megan** have been working with **Staffan** to develop the scripts for the films. The first film is the longer PHACS documentary. **Claire** will share the documentary with the CAB shortly. **Claire** and **Megan** are currently working on the CAB film. The film is about 5 minutes long. The film includes individual interviews with CAB members. It also includes footage from the CAB group discussion about story circles. Both films will be shown at the Spring Retreat and Fall Network Meeting. **Claire** and **Megan** will brainstorm with the CAB and other PHACS members about how to disseminate the film.

**NOTE: The next CAB call will be on Thursday, February 23, 2017 at 12:00 pm EST.**