

**CAB Conference Call
October 22, 2020
12:00 ET
Meeting Minutes**

Participants:

Anisa	Harvard University
Deb	Harvard University
Carol	Bronx-Lebanon Hospital Center
Claire	Harvard University
Falon	University of Colorado, Denver
Gena	University of Miami
Haleigh	FSTRF
Jennifer	University of Colorado, Denver
Joel	University of Puerto Rico
Julie D.	Westat
Julie H.	University of Alabama, Birmingham
Kate	Harvard University
Kimbrae	Texas Children's Hospital
Kylie	Texas Children's Hospital
Latonia	University of Illinois, Chicago
Liz	Harvard University
Lourdes	San Juan Hospital
Megan	Westat
Raiko	University of Colorado, Denver
Rosetta	Bronx-Lebanon Hospital Center
Stephanie M.	University of California, San Diego
Stephanie S.	University of Miami
Tatania	Tulane University
Theresa	Texas Children's Hospital

• **APPROVAL OF MINUTES**

The minutes from the September 24, 2020 call were approved with no changes.

• **HEALTH OUTCOMES AROUND PREGNANCY AND EXPOSURE TO HIV/ARV (HOPE)**

Dr. Deb Kacanek thanked the CAB for inviting her to talk about the Health Outcomes Around Pregnancy Exposure to HIV/ARV (HOPE). **Deb** talked about the study aims. The main aims are to set up the HOPE cohort, to look at the HIV-related and general health of women living with HIV (WLHIV), and to assess maternal health for WLHIV. This means studying the impact of having a child. This includes looking at the positive and negative health outcomes that come with the process of caring for children. The goal is to enroll 1,630 WLHIV.

HOPE is looking to enroll WLHIV including:

1. "Nulliparous" women: 200 WLHIV who have not had children before. These women will be 30-years-old or younger. These women will be recruited from HOPE-recruiting SMARTT sites.
2. Pregnant women: 416 WLHIV who are 40-years-old or younger. These women will be newly enrolling in SMARTT during pregnancy or at delivery.
3. Postpartum/parenting women: This group will be divided in two groups.

- a. 466 SMARTT WLHIV who are 40-years-old or younger. This group of women should already be enrolled in the Women's Health supplement.
 - b. 208 Non-Women's Health Supplement SMARTT WLHIV who are 40-years-old or younger. This group of women should have children who are 4-years-old or younger.
4. 340 WLHIV who are participating in AMP Up and AMP Up lite.

Deb talked about the visit activities. There will be an enrollment visit where participants will have their body measurements taken. Researchers will collect laboratory specimens at this visit. They will also interview participants about their mental health. Some of their information will be obtained from medical records. Participants will also be asked to fill out an online survey. Finally, participants will be given the option to wear a device that is like a Fitbit. The devices will be used to look at activity such as their heart beat and sleeping patterns.

Women can join the study before, during, and after pregnancy. If they enroll when they are pregnant, there will be an enrollment visit, a delivery visit, and a 6-week postpartum visit. These visits will be in person. The 1-year postpartum visit and the annual follow-up visits will be virtual.

HOPE researchers want to understand how certain factors affect women's health. These factors include structural factors and community and institutional factors. They also include interpersonal/family factors and individual factors.

Deb described the factors. She gave the following examples of each of the groups of factors:

1. **Structural:** Stigma, poverty, racism, discrimination, insurance/access to care
2. **Community and institutional:** Health Care System, Social Capital, Neighborhoods
3. **Interpersonal/Family:** Social Network, Intimate Partner Violence, Patient/Clinician Relationship, Social Support, Social Norms, Social Stress
4. **Individual:** Biological, Demographic (age, education, housing stability, health literacy), Attitude/Beliefs/Behaviors (Self-efficacy, Pregnancy Intention, Health Care Seeking)

Deb talked about some discussion questions:

1. **The study will be inviting women who are not mothers or have not given birth to participate. What do you suggest about making the study something they would want to join and stay in? What suggestions do you have for making them feel welcomed?**

Feedback from the CAB included:

- The atmosphere and staff need to make women feel welcomed.
- It is appealing to women when they know they are part of something greater.
- Researchers should highlight that this is a study for women's health.
- The language needs to be inclusive and make sure it does not offend any women that did not want to have children or women who could not have children.
- Information about the study could come from their doctor.

2. **Do you think there will be women who would want to join HOPE but might not be interested in joining SMARTT?**

Some CAB members mentioned that parents do not want their children to go through some of the activities that come with being part of a study such as getting their blood drawn.

- 3. The annual follow up visits for HOPE will be remote, meaning participants will not need to come to the clinic and will be asked to complete a 45-minute recorded survey once a year. How do you feel about the remote visits? What challenges should we expect? What suggestions do you have for addressing them? What would be good about the design? How will women feel about completing the online survey and not having in person visits?**

Feedback from the CAB included:

- During the remote visit, participants should be given the option to have a Study Coordinator read the questions in-person instead. The staff member could enter the participant's responses into the computer. This would be helpful if participants do not have a computer at home. There may be many participants who only have phones.
- Make remote visits interactive with things like quizzes or games that can help participants be engaged.
- Add the option to stop and save the survey to finish it at a later time.
- It would be helpful to have Study Coordinators assist in reading questions to participants remotely or in-person.
- Send birthday cards and holiday cards to participants.

- 4. One part of the remote assessments involves wearing a device like a Fitbit to assess sleep, physical activity and heart rate. What do you think about this? What concerns you about this?**

Feedback from the CAB included:

- Reassure participants that their information will not be shared.
 - It would be helpful if the device was waterproof.
 - Consider using a smartphone app instead of a device so people can enter their own data.
- Deb** mentioned that participants may have phones that could not access an app. Using an app may also be time consuming.

Deb invited the CAB to join a task force to continue to talk about these discussion questions. **Kim, Gena, Raiko, Rosetta,** and **Latonia** volunteered to join follow-up calls. Theresa mentioned that there is a CAB meeting at Texas Children's Hospital. She invited **Deb** to participate in their local CAB meeting in November.

NOTE: The next CAB call will be on Thursday, November 19, 2020 at 12:00 pm ET.