

**CAB Conference Call
April 22, 2021
12:00 ET
Meeting Minutes**

Participants:

Anisa	Harvard University
Carol	Bronx-Lebanon Hospital Center
Claire	Harvard University
Deb	Harvard University
Eduardo	Harvard University
Falon	University of Colorado, Denver
Gena	University of Miami
Haleigh	FSTRF
Julie H.	University of Alabama, Birmingham
Karim	Westat
Kimbrae	Texas Children's Hospital
Kylie	Texas Children's Hospital
Lesley	Texas Children's Hospital
Liz	Harvard University
Mandy	Harvard University
Mary Anne	Westat
Raiko	University of Colorado, Denver
Sannita	University of Miami
Sharon H.	Harvard University
Shary	University of Southern California
Stephanie S.	University of Miami
Tatania	Tulane University
Tracy	Westat
Vinita	Westat

• **APPROVAL OF MINUTES**

The minutes from the March 25, 2021 call were approved with no changes.

• **HOPE STUDY/WOMEN'S HEALTH UPDATE – DR. DEB KACANEK**

Claire introduced **Deb KacaneK** from the HOPE study. Deb presented updates of the study since the October 2020 CAB meeting. **Deb** thanked the CAB for their feedback after the last meeting.

HOPE updates since October 2020:

- October – December 2020: The protocol was finalized. The forms that researchers use to collect the data were finalized. **Deb** thanked **Kim, Claire, Liz,** and **Anisa** for their help on finalizing the protocol.
- December 2020 – January 2021: The protocol was reviewed by the HOPE team and the PHACS Scientific Leadership Committee (SLC)
- February – March 2021: The protocol team sent the protocol to the Harvard Longwood Campus Institutional Review Board (IRB). IRBs are responsible for reviewing research protocols. They make sure that participants' rights and safety are protected.

- March – April 2021: The HOPE protocol team responded to the IRB’s questions about the protocol.
- April 2021: The IRB approved the HOPE protocol.

Deb explained the next steps for HOPE:

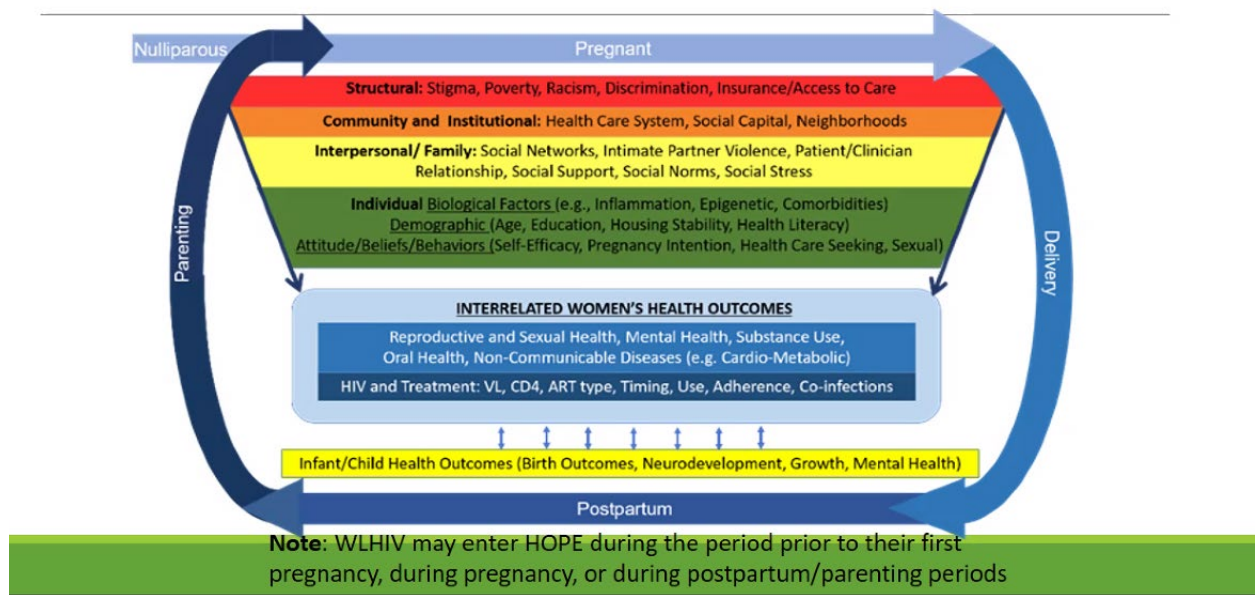
- Test and finalize questionnaires, study forms, and recruitment materials
 - CAB members can participate in the process
- Open the HOPE study at HOPE sites;
- Develop a Manual of Operations and Procedures. Create and a protocol registration system;
- PHACS Spring Network Meeting Day 2 (May 6): That day will be dedicated to HOPE and Women’s Health.
 - Invited speaker. This speaker will talk about issues of environmental justice in her work. This includes reproductive health and women’s health.
 - There will be a panel at the end of the day moderated by **Kim** – “Hopes for HOPE”
- Site training (June 2021); and
- Open study to start enrolling women by July 2021.

Deb reviewed the HOPE’s study aims:

- The HOPE Cohort will include 1,600 women living with HIV (WLHIV);
- To study the HIV-related and general health of WLHIV; and
- To study maternal health of WLHIV. This includes caregiving and social support of children who have/do not have health conditions.

Deb explained that HOPE is the first protocol in PHACS that will look at influences on women’s health. Influences include structural influences like stigma, poverty, racism, discrimination, and access to care. The researchers will also look at community influences like healthcare systems and neighborhoods. They will also look at family influences such as social networks, intimate partner violence, and social stress. Finally, they will look at individual influences such as housing stability, attitudes and behaviors, and biological factors like inflammation and comorbidities. Comorbidities are when a person has more than one health condition at the same time. The purpose is to understand how these factors affect women’s health.

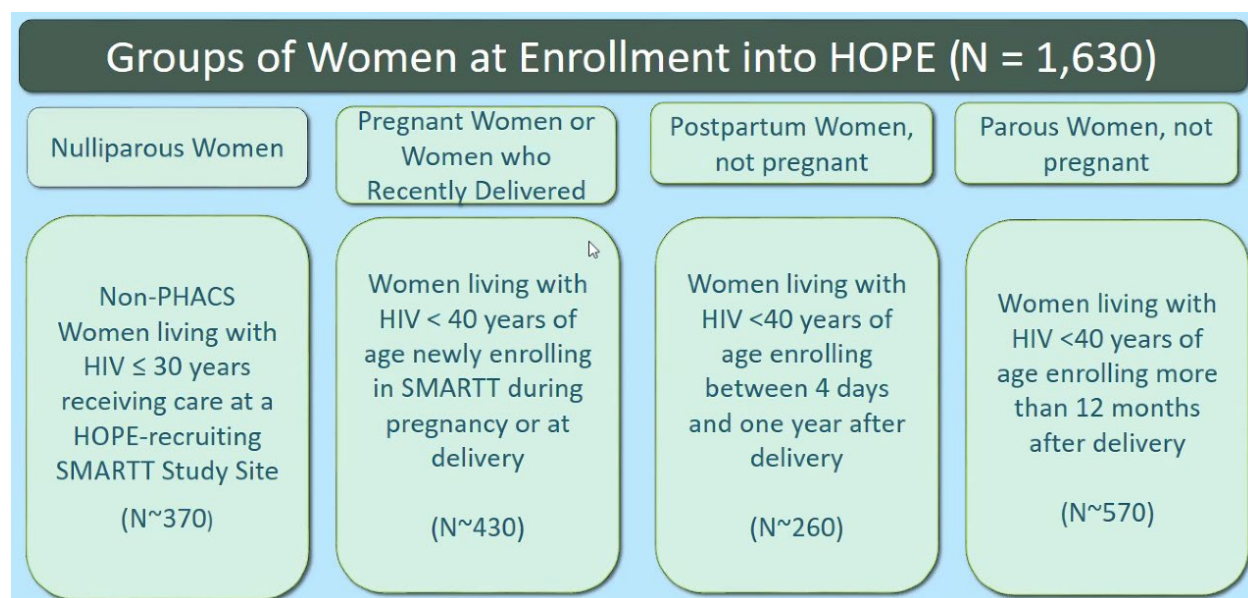
HOPE Study – Conceptual Framework



Deb spoke about the research domains:

- Reproductive health;
- HIV disease progression and care;
- Mental health;
- Stigma, discrimination;
- Cardiometabolic health;
- Co-infections (COVID-19); and
- Substance use.

Deb showed the groups of women at enrollment into HOPE:



Deb explained that the HOPE team needs the help of CAB members. CAB members can help point out challenges and resources the HOPE team may need for some of the study activities. The team also needs to know what other questions the researchers may not have considered. The topics needing CAB feedback are:

- Geocoding and influences of the neighborhood on health;
- Stressors in a women’s life (experiences of discrimination and racism); and
- Sources of resilience: What helps people keep going even in times of trouble? Where do you find strength?

Deb said that the first topic to discuss is the geocoding. **Deb** needs feedback on the best way to collect a participant’s address. Geocoding helps researchers identify characteristics of the community where people live. These characteristics can be found in the census. Some of the characteristics are:

- People with health insurance;
- People below the poverty level;
- How close people are to a health care center; and
- Women’s risk of diseases such as asthma, cardiovascular disease.

Some of these characteristics are linked to forms of structural racism. HOPE participants will be asked to provide their address. The address will then be “geocoded.” This means that the code will be assigned to a census tract (area with a population between 1,200 and 8,000 people). **Deb** said that geocoding is a new term for many people. This is why the researchers need feedback from the CAB members.

Claire asked the CAB members for their opinions on how the researchers should explain geocoding to HOPE participants. **Claire** showed a CDC website with a US map divided by census tracts. **Claire** explained that if HOPE participants are not comfortable providing their address, they could give an address close to their home. **Deb** explained that the participants’ addresses will only be seen by 1 or 2 study researchers. The majority of the HOPE team will only see the characteristics related to the census

tract. This means the researchers would only be looking at characteristics like percentage of people who don't have health insurance.

Kim asked if other PHACS protocols will look at geocoding. She wondered if it could be used for advocacy and legislation. **Deb** explained that geocoding has been used in other studies as well as health departments. It could be used for advocacy and legislation. **Kim** mentioned that she would be willing to give her address based on how the HOPE team plans to use it. She explained that she is happy to help her community.

Tatania asked if people could give their zip code, instead of the full address. **Deb** answered that zip codes in United States cover large areas with different characteristics. Another option could be that the participant provides the nearest cross street.

Kim suggested sharing the nearest landmark or building (post office, library, or grocery store). **Stephanie** said that zip codes cover large areas. This means zip codes will not be able to target the characteristics of the area that the participant lives. The best way is to use the address. It is important to find areas where there is a need, especially for health care access.

Shary said it is important to explain in creative ways how a participant's address becomes a number. It was suggested that researchers emphasize the purpose, possible outcomes, and benefits of providing a complete address. The approach used is important to help people feel comfortable with sharing their information. It is also important to highlight the confidentiality of a participant's information. Researchers should provide a simple explanation of how their information will be used. She asked if the information will be provided in Spanish. **Deb** replied that they are working on the English informed consent form right now and are planning to create a video in both English and Spanish. **Claire** said that the information could be animated with two versions (English and Spanish). **Deb** said that creating a resource for explaining the information would be great and she is willing to continue the conversation about the study at another time.

• **HEALTH EDUCATION AND COMMUNITY CORE (HECC) UPDATE**

- **Claire** introduced the new members of the Harvard School of Public Health team, **Mandy** and **Eduardo**. Mandy is the new Digital Health Communication Specialist. **Eduardo** is the new Site Coordinator.
- Spring Virtual Retreat, May 5-7: Everyone is welcome to join! Some of the retreat topics are racial justice, HOPE, and TERBO BRAIN.

NOTE: The next CAB call will be on Thursday, May 27, 2021 at 12:00 pm ET.