

**CAB Conference Call
June 25, 2020
12:00 EST
Meeting Minutes**

Participants:

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|----------------------|-------------------------------------|
| Alejandra | Texas Children's Hospital |
| Anisa | Harvard University |
| Antionette | University of Miami |
| Carrie | University of Colorado, Denver |
| Claire | Harvard University |
| Deb | Harvard University |
| Falon | University of Colorado, Denver |
| Gloria | University of Florida, Jacksonville |
| Joel | University of Puerto Rico |
| Julie H. | University of Alabama, Birmingham |
| Julie D. | Westat |
| Haleigh | FSTRF |
| Kimbrae | Texas Children's Hospital |
| Liz | Harvard University |
| Lourdes | San Juan Hospital |
| Megan | Westat |
| Paige | University of Alabama, Birmingham |
| Raiko | University of Colorado, Denver |
| Shelley | Texas Children's Hospital |
| Stephanie M. | University of California, San Diego |
| Stephanie S. | University of Miami |
| Theresa | Texas Children's Hospital |
| Veronica F. | University of California, San Diego |
| Veronica S.R. | University of Puerto Rico |

• **APPROVAL OF MINUTES**

The minutes from the June 11, 2020 call were approved with no changes.

Claire followed up about the 23rd International AIDS Conference (AIDS 2020). The conference will be held online. **Enise**, PUG Vice Chair, recorded an oral presentation for AIDS 2020. Her presentation is titled "My Life, My Story: Growing up with HIV." This presentation will air on demand during AIDS 2020. This powerful presentation was presented as part of "The very long and winding road for young people living with HIV: Stories and solutions from youth to youth" session. This session will air during the On-demand Bridging and Symposia.

Several pre-conferences are attached to AIDS 2020. One of the pre-conferences will be 6th Workshop on Children and Adolescents HIV-Exposed and Uninfected. **Kimbrae** and her son **Gamon**, and **Stephanie** and her daughter **Lexi** recorded a conversation for the pre-conference. This conversation was about HIV, stigma, advocacy, and maternal disclosure. The conversation was recorded in a StoryCorps format. **Kimbrae** will also participate on a live panel later in the workshop.

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

Deb talked about HOPE. **Deb** explained that there is a core team who has been meeting to write the protocol. They have been working on it since early April 2020. The Notice of Award has not yet been received. That means that even though the team expects the study to be funded, they do not have

official word that it has been funded. The team is going to be growing over the coming months. It is important to the team that the CAB is involved. CAB members are encouraged to be involved in ways that are the most helpful to them.

Deb reviewed the study aims. The first aim is to establish the HOPE cohort. There will be several sources of recruitment for HOPE. HOPE will be recruiting women living with HIV (WLHIV)

One group of participants will be nulliparous women. This means women who have not given birth. For this group, they hope to recruit women younger than 30 who were not in PHACS. The goal is to recruit 200 nulliparous women.

The HOPE study will also recruit pregnant women. These women will be less than 40 years old. They will be newly enrolling in SMARTT during pregnancy or at delivery. The goal is recruit 416 pregnant women.

The HOPE study will also recruit postpartum and parenting women. This would include WLHIV who are less than 40 years old. They will be already enrolled in the Women's Health Supplement. The goal is to recruit 466 women. The study will also enroll women who did not enroll in the supplement, but meet the criteria. The goal is to include 208 women.

Finally, the HOPE study will recruit 240 AMP Up and AMP up Lite WLHIV since birth. The nulliparous women will be compared with this group.

Deb reviewed the second and third aims. The second aim is to look at the HIV-related and general health of WLHIV in the HOPE cohort over their reproductive lives. The third aim is to assess maternal health of WLHIV as it relates to caregiving and social support of children with and without adverse health conditions/events. For this aim, the team is very interested in looking at women who have caregiving responsibilities. They want to know if the caregiving responsibilities and/or their child's health status has an impact on their health of WLHIV.

Deb talked about visits for the HOPE study. There will be one in-person enrollment visit. Women could be enrolled at the time of delivery. They can also be enrolled while they are not pregnant. At the visit, they will have body measurements. They will also have their blood pressure taken. They will complete an online survey. There will be some chart abstraction. That means that with consent, the researchers will look at some of their medical records. There will be some specimens collected. There will also be some activity monitoring such as using a "Fitbit."

For women who enroll during pregnancy, there would be extra visits. These visits include a delivery visit and a 6-week postpartum visit. For everyone, there would be follow up visits every year. Those visits will be virtual. If women are enrolled in SMARTT with their children, they will also have the option to complete their visit in person combined with a SMARTT visit.

Deb talked about the framework for the HOPE study. The way the team envisions health is to think about the health of the woman as a whole across their reproductive life. This includes whether they are pregnant or never become pregnant. The team wants to recognize that everything a woman goes through during this time could affect health. The team also notes that there are factors that affect health at multiple levels. These factors can include structural, community and institutional, interpersonal/family, and individual factors. The team also wants to note the importance of baby and child health outcomes. These outcomes may be interconnected with the other outcomes.

Deb talked about the research domains. The domains include reproductive health, HIV disease progression and care engagement, and cardio metabolic health. Domains will also include co-infections (like COVID-19), substance use, and mental and psychosocial (racism, experiences of stigma, etc.) determinants.

Deb reviewed the proposed aims for each domain. The CAB was encouraged to make recommendations.

Domain: HIV Disease Progression & Care Engagement
Proposed Aims:

- *To investigate the commonness, changes in, and HIV history-related predictors of HIV care continuum outcome component. This includes linkage to HIV care, retention in HIV care, adherence, viral suppression, immune status. This would be studied across the reproductive life course among women.*
- *To study individual, interpersonal, social and structural determinants of HIV care continuum-related outcomes. This includes linkage to HIV care, retention in HIV care, adherence, viral suppression, and immune status. This would be studied across the reproductive life course among WLHIV.*
- *To describe the transition from pregnancy care to postpartum HIV care. To look at barriers and ways to help successful transition.*

Theresa suggested looking at women who have private health insurance. It may be interesting to see how the availability of insurance can help health outcomes. Some women might not have insurance. This means they may not be able to access care. **Deb** agreed that there are a lot of issues around connection to services and health. This is more than just writing down whether a referral was made.

Kimbrae talked about the HIV disease progression & care engagement domain. **Kimbrae** appreciated the domain. It is helpful to include women who have not had children.

Domain: Stigma, Racism and Social Determinants of Health

Summarized Proposed Aims:

- *To describe predictors and health related consequences of internalized HIV stigma and racism among WLHIV. This would be studied across the reproductive life course.*
- *To assess the relationship of structural racism and experiences of racism to the health of WLHIV.*
- *To find predictors and health consequences of HIV disclosure to intimate partners and women's wider social networks.*

Deb explained that there are disparities in health outcomes. The researchers want to shine a light so that interventions can be made to address disparities. The researchers want to look at racism and stigma in the context of health care. They also want to look at those factors in daily life. **Liz** explained that it is important that what is important to women of color is captured in the aims.

Domain: Reproductive Health

Summarized Proposed Aims:

- *To find and talk about factors associated with:

 - *Pregnancy outcomes*
 - *Pregnancy complications**
- *To assess knowledge and awareness of HIV prevention practices and safer sex practices.*
- *To determine commonness of sexually transmitted infections (STIs) and find factors associated with getting STIs.*

Deb explained that the study will be looking at participant use of pre-exposure prophylaxis (PrEP). PrEP is a way for people to prevent HIV by taking a pill every day. The study will also look at how undetectable = untransmittable (U=U) affects sex practices. This domain looks at sexual behavior. It also looks at sexual satisfaction. This means how the whole person is doing in this domain. It is not just looking at risk for disease.

Shelley asked whether the surveys would include questions about use of contraception. **Deb** explained that the surveys will cover contraception. The team is interested in people's perceptions of contraception. They want to know if there are reasons some methods are used over others. There may be reasons someone switches methods. The team also wants to know whether contraception behaviors align with the outcomes someone wants.

Domain: Cardiometabolic Health

Summarized Proposed Aims:

- *To look at ARV use and weight change.*
- *To look at how someone got HIV, immune status, viral control, ART regimen, and high blood pressure.*
- *To look at ART use and gestational diabetes.*
- *To study the influence of sleep and activity on cardiometabolic health among women living with HIV*

Deb Explained that sleep and activity will be studied using the activity devices (i.e., Fitbit). The devices can monitor sleep, activity, and stress. There are ways to use that data to answer questions about health.

Domain: Mental Health and Psychosocial Determinants

Summarized Proposed Aims:

- *Describe the commonness, onset, remission, and/or recurrence of psychiatric disorders and substance use disorders among WLHIV.*
- *To look at individual, HIV disease, treatment, pregnancy-related, and psychosocial factors associated with psychiatric and substance use disorders among WLHIV.*
- *To find out the relationship of psychiatric and substance use disorders to adherence and HIV disease outcomes among WLHIV.*
- *To study the connection between violence exposure, psychiatric and substance use disorders and HIV disease factors to a) hypertension; b) adverse pregnancy outcomes; c) adverse children neurodevelopmental outcomes.*

Domain: Substance Use

Summarized Proposed Aims:

- *To look at changes in substance use behavior among WLHIV over time. To explore patterns unique to individuals who experience reproductive life events such as pregnancy, the first year postpartum, and early years of parenting.*
- *To look at the relationship of substance use among pregnant and postpartum WLHIV. To look at the association with child health outcomes, including child neurodevelopment.*
- *To look at the relationship of substance use among WLHIV across the reproductive life on HIV-related outcomes, including HIV control and HIV care.*
- *Find predictors of substance use among WLHIV across reproductive life. This includes mental health, political/public health, social determinants of health, and health care systems/processes.*

Shelley asked whether data would be collected by online survey. **Deb** explained that it would be collected by an online survey. **Shelley** explained that the substance use questionnaires in SMARTT can be difficult. It seems like doing the survey face-to-face may make it hard for women to feel that they can be honest. Doing the surveys online may be more comfortable.

Domain: Co-Infections

Summarized Proposed Aims:

- *To look at the incidence, hospitalization rates, other characteristics of, and factors associated with COVID-19 among WLHIV of reproductive age*

NOTE: The next CAB call will be on Thursday, July 23, 2020 at 12:00 pm EST.