

**CAB Conference Call  
September 27, 2018  
12:00 EST  
Meeting Minutes**

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**Participants:**

<b>Alex</b>	FSTRF
<b>Andrea</b>	Jacobi Medical Center
<b>Anisa</b>	Harvard University
<b>Caroline</b>	NIH, NICHD
<b>Carrie</b>	University of Colorado, Denver
<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>Gena</b>	University of Miami
<b>Jeanie</b>	University of Southern California
<b>Jennifer</b>	University of Colorado, Denver
<b>Joel</b>	University of Puerto Rico
<b>Juanita</b>	Tulane University
<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>Latonia</b>	University of Illinois, Chicago
<b>Lawrence</b>	Harvard University
<b>Lesley</b>	Texas Children's Hospital
<b>Leslie</b>	Texas Children's Hospital
<b>Liz</b>	Harvard University
<b>Lourdes</b>	San Juan Hospital
<b>Megan</b>	Westat
<b>Michelle</b>	Harvard University
<b>Morten</b>	Bronx-Lebanon Hospital Center
<b>Raiko</b>	University of Colorado, Denver
<b>Shannon</b>	University of Alabama, Birmingham
<b>Stephanie</b>	University of California, San Diego
<b>Stephanie</b>	University of Miami
<b>Tatania</b>	Tulane University
<b>Theresa</b>	Texas Children's Hospital
<b>Veronica</b>	University of California, San Diego

• **APPROVAL OF MINUTES**

The minutes from the August 23, 2018 call were approved with no changes.

• **PREGSOURCE**

**Dr. Caroline Signore** talked about PregSource. PregSource is an online research registry. PregSource opened in October 2017. PregSource enrolls pregnant women. Through PregSource, pregnant women talk about their pregnancies through an online program. Researchers want to learn about the typical experience of pregnancy. PregSource asks for data on physical and emotional experiences. The online program also links to pregnancy resources.

One of the goals of PregSource is to gather information about pregnancies from a wide range of women. This includes women living with chronic illness. It also includes women living with disabilities. Another goal of PregSource is to put together data that will help future research studies.

Women who are pregnant can enroll in PregSource. They can complete the informed consent process online. Once enrolled, they create a username and password. The login information is used to get on to the online program. Participants can then do their surveys online. Participants continue to complete surveys throughout pregnancy. Some surveys will be done postpartum.

Participants can print their surveys and share them with their doctors. Participants are also able to compare their experiences to other participants. The online PregSource program does not have any pop ups or ads. Participants' personal information will not be sold or shared.

PregSource is also interested in learning about online data studies in general. Researchers want to learn how many participants will join an online study. They are also interested in learning how many participants will regularly enter data while they are pregnant. After pregnancy, researchers want to know if participants are still entering data online when they are busy taking care of their new babies.

PregSource will include surveys about due dates and health history. Surveys will also look at demographics. Some surveys will focus on monthly age-specific data. PregSource will also use "trackers" to follow participants. Participants can enter data into the trackers such as weight and medication use. Participants will be able to track this data over the course of their pregnancy.

Resources in PregSource will include over 450 articles. These articles will be available in an online resource library.

PregSource researchers are working on creating a Spanish online program. Researchers are also putting together new surveys. New surveys may focus on postpartum and baby health up to 36 months. New surveys will also focus on topics for special populations such as women living with chronic illness or disabilities. PregSource will also be adding a Twitter feed and a portal for researchers.

**Leslie** asked about time commitment. **Dr. Signore** explained that most surveys take 3-5 minutes to complete. Trackers can be completed in 3 minutes. **Leslie** asked about whether the surveys will be accessible on smart phones. **Dr. Signore** explained that the online platform will be accessible on many different devices.

**Dr. Signore** explained that PregSource is interested in collaborating with other studies like PHACS.

## • **WOMEN'S HEALTH WORKING GROUP LEADERSHIP**

Due to connectivity issues, the Women's Health Working Group (WG) discussion was rescheduled. The Women's Health WG will meet with the CAB on Friday, October 26, 2018 at 12:00 PM EST.

**NOTE: The next CAB call will be on Thursday, October 25, 2018 at 12:00 pm EST.**