CAB Conference Call July 23, 2020 12:00 EST Meeting Minutes

Participants:

Anisa Harvard University

Carrie University of Colorado, Denver

Claire Harvard University

Exzavia Children's Diagnostic and Treatment Center

Falon University of Colorado, Denver **Gloria** University of Florida, Jacksonville

Juanita Tulane University

Julie H. University of Alabama, Birmingham

Julie D. Westat Haleigh FSTRF

Kimbrae Texas Children's Hospital
Kunjal Harvard University
Liz Harvard University
Lourdes San Juan Hospital

MeganWestatNatalyWestat

RaikoUniversity of Colorado, Denver **Shannon**University of Alabama, Birmingham **Stephanie M.**University of California, San Diego

Stephanie S. University of Miami Texas Children's Hospital

Trinise Tulane University

Veronica University of California, San Diego

APPROVAL OF MINUTES

The minutes from the June 25, 2020 call were approved with no changes.

PHACS 2020 FALL NETWORK MEETING

Megan talked about the PHACS 2020 Fall Network Meeting. Due to COVID-19 travel concerns and the PHACS 2020 transition, the Fall Network Meeting has been cancelled. The PHACS teams will be very busy in the coming months as they start up PHACS 2020. There will not be a virtual network meeting. However, the CAB may consider holding a virtual retreat. **Megan** acknowledged that it may be difficult to meet virtually for a long period of time. It can be tiring to sit in front of the computer for too long. The CAB may consider splitting a virtual retreat up over a couple days. The CAB will discuss options for a virtual retreat during the next CAB call.

• NEW IDEAS FOR RESEARCH OF COVID-19 IN PHACS, SPECIMEN COLLECTION

Dr. Kunjal Patel talked about specimen collection in PHACS. **Kunjal** thanked the CAB for their feedback. CAB feedback can help PHACS decide on the best ways to collect specimens.

Kunjal mentioned that **Dr. George Seage** talked about COVID-19 and PHACS during the 2020 Spring Virtual Retreat. **George** mentioned that COVID-19 has created new challenges for research. He

encouraged the researchers to think creatively about ways PHACS can learn more about COVID-19 and HIV. He asked the Working Groups (WGs) to come up with scientific aims that help contribute to knowledge about COVID-19. Without knowledge, scientists cannot intervene and help fight COVID-19.

Kunjal is Co-Chair of the Complications WG. The Complications WG has been thinking about their goals for COVID-19 research in PHACS. The challenge is that PHACS researchers do not yet know the impact of COVID-19 in PHACS participants. It is important to follow PHACS participants to learn how COVID-19 affects them.

The Complications WG started thinking about ways PHACS can learn about if a participant has gotten the coronavirus. **Kunjal** explained that there are some ways to test for current or previous coronavirus infection. The first way is through a nasal swab. That detects current infection. It shows that the virus is in the nose and back of throat. There are new technologies about how to test for the coronavirus at home.

Kunjal explained that once someone gets the coronavirus, their body will respond. This means the body will try to clear the virus. The way the body does this is by creating antibodies. Antibodies are proteins created by the body's immune system. Antibodies help fight a virus out of the body. It is hoped that antibodies stick around in the body. This is so that if a person gets a virus again, the antibodies come out to fight it again quickly. Scientists can find out if someone has had the coronavirus before by looking at antibodies. Scientists can look at antibodies in blood samples. In PHACS, researchers have to think about possibly measuring current infection and past infection through antibodies.

Kunjal talked about how COVID-19 has disrupted how people access healthcare. Some people may not feel comfortable going to medical clinics right now. Additionally, some medical clinics have had to shut down.

Kunjal talked about at-home specimen collection. It may not be possible for people to go into a PHACS site for specimen collection. There are new technologies that allow people to collect their own specimens at home. These include: 1) saliva; 2) nasal swab; 3) blood; and 4) dried blood spot collection.

Kunjal talked about option #1, <u>saliva collection</u>. This type of collection detects current coronavirus infection. If this kit were to be used in PHACS, it would be shipped to the participant's home. The participant would follow the instructions and give their saliva sample. They would then mail the kit back to the testing company. The testing company would give the result to the PHACS researchers, who would then give the results to the participants.

Kunjal talked about option #2, <u>nasal swab collection</u>. This type of collection detects current coronavirus infection. This kit includes a tube and a nasal swab. It has instructions about how to insert the swab in the nose, put the swab in the tube, and mail back to the testing company.

Kunjal asked whether CAB members preferred option 1, 2, or neither. **Kim** explained that she prefers option 1, saliva collection. The nasal swab collection might be tough for a child. Children might be excited to spit into a cup. Parents could call it a "spitting contest." **Kim** feels that the maturity of a child would determine which option would be the most appropriate. Ages 3+ may do well with saliva collection.

Stephanie M. talked about the specimen collection with her children. A nasal swab might work out better for toddler aged children. Parents might be able to collect samples while the children are sleeping. **Stephanie's** children preferred option #1, saliva collection.

Stephanie S. talked about option #2, nasal swab collection. **Stephanie S.** thought that some parents may see the instruction manual and panic. They may worry they would not do it correctly. They may worry they would hurt their child.

Julie H. talked about specimen collection. Spitting can be difficult for some children. There used to be saliva collection in SMARTT. Her site found that it was tough for children to get enough saliva to meet the requirement. She preferred option #2, nasal swab collection. Nasal swabs may be easier.

Veronica talked about instruction manuals for at-home specimen collections. Some parents may be confused or may not be able to read the manuals. It could be helpful for them to get some additional instruction from PHACS site staff.

Kunjal asked CAB members what would be the best method for adults. **Stephanie M.** prefers option #2, nasal swab collection. **Kim** prefers option #1, saliva collection. **Kunjal** explained that the at-home nasal swab collection is not the same as the nasopharyngeal swab. The nasopharyngeal that some people may have experienced at a medical clinic goes very far up the nose. The at-home nasal swab does not go very far up the nose.

Julie H. wondered if site staff would send out at-home specimen kits and instructions. **Kunjal** explained that it has not yet been decided. They could be sent by site staff. They could also be sent by the Data Management Center (DMC).

Trinise wondered if parents could pick up the kit at their PHACS site. She also wondered if they would have to pay for it. **Kunjal** explained that PHACS would pay for the research kits. That means PHACS families would not have to pay for it.

Claire asked whether participants would be given a choice of options. **Kunjal** explained that nothing has been decided. It would depend on funding. It may be helpful to have flexibility. This is because one option might not be best for everyone.

Claire talked about confidentiality. Some people may be concerned that their results would be shared with their county, state, or employers. **Kunjal** explained that PHACS would maintain confidentiality as much as possible. However, all COVID-19 testing is being sent to the government. The data is coded. It does not include names. This is because reporting is important for public health.

Kunjal talked about option #3, <u>blood collection</u>. Some PHACS researchers call this a "ladybug" device. This type of collection detects previous coronavirus infection. It does so by measuring antibodies. The device sticks to the arm. Several tiny needles go into the arm at once and pull out a small amount of blood.

Kunjal talked about option #4, <u>dried blood spot collection</u>. This type of collection also detects previous coronavirus infection. It does so by measuring antibodies. It is a finger prick collection. A tiny needle pricks the finger. The participant then squeezes drops of blood into the test kit. Dried blood spot collection is done commonly in Africa. It is used to do HIV viral load testing.

Kunjal asked whether CAB members preferred option 3, 4, or neither. **Stephanie M.** prefers option #3, blood collection (ladybug) for herself and her children. **Kim** also prefers option #3 for herself and her children. Children may be scared of the finger prick. **Trinise** prefers option #3.

Claire asked if CAB members had concerns about options 3 or 4. **Kim** talked about the option #3, blood collection (ladybug). Parents may need to distract their children so that they are not scared of the ladybug on their arm. **Stephanie M.** thought that the device could be used on all ages. Option #4 may be difficult for young children. They may not like their fingers to be squeezed.

Kunjal talked about the ladybug. PHACS is hoping to get samples from the manufacturer. They may be looking for people to test it out on themselves and see how it feels. **Kim** thought some parents may want to paint the ladybug to look like a ladybug.

Claire wondered whether CAB members would like an instruction video to accompany the ladybug. **Veronica** wondered whether small children might be intimidated by the ladybug. **Raiko** thought that the ladybug looked cute. She did not think small children would be scared of it.

Kunjal explained that the ladybug is a one-time device. This is for patient safety so that the needles cannot be reused. The needles disappear into the device after they are used.

NOTE: The next CAB call will be on Thursday, August 13, 2020 at 12:00 pm EST.