## CAB Conference Call July 25, 2024 12:00 ET Meeting Minutes

## **Participants:**

**Andrea** Jacobi Medical Center **Antoinette** University of Miami

**Carol** Bronx-Lebanon Hospital Center

**Chitara** Ann & Robert H. Lurie Children's Hospital **Eduardo** Harvard T.H. Chan School of Public Health

**Exzavia** Children's Diagnostic & Treatment Center, Ft. Lauderdale

**Falon** University of Colorado, Denver **Gena** University of Miami, Florida

Joy Westat Karim Westat

Kim Texas Children's Hospital
Kylie Texas Children's Hospital

**Liam** FSTRF

Mandy Harvard T.H. Chan School of Public Health

Rosalva UCSD

Samantha Tulane University

Sannita

**Tameka** St. Jude Children Research Hospital

# • APPROVAL OF MINUTES

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

#### ICEBREAKER

Mandy led the icebreaker.

## SPACES FOR SELF-CARE

**Eduardo** led the space for self-care.

### HECC UPDATES

**Mandy** talked about the poster presentation that was accepted on the AIDS 2024 Conference. The conference is being held in Munich, Germany from July 22 – 26th. Claire presented the poster on July 23: The Health Education and Community Core (HECC): A model of community engagement in the U.S.-based Pediatric HIV/AIDS Cohort Study (PHACS) Network. The poster displays the impact of community engagement in PHACS research process and the structure of community groups. It highlights how PHACS and HOPE scientific agendas reflect participant priorities. The HECC model is described as a collaborative effort between individuals with different roles in PHACS. It presents the importance of everyone sharing their expertise and experiences. PHACS community groups are described in the poster:

- CAB
- HOPE CAB

- Spanish CAB
- · Peers United Group
- Task Force

Several QR codes were included with links to: Lay summaries, Coco activity pages and other HECC work

During the conference, Claire had the opportunity to talk with people from different countries interested in implementing the model.

The conference theme is "Putting People First". Focus on the person and the collaboration between participants and clinicians. At the conference, topics included:

- Long-acting ARV injection: Lenacapavir. The medication has shown 100% efficacy in HIV
  prevention in women of South Africa. Several protests occurred and disrupted some of the
  sessions. Protesters were advocating for access to long lasting ARVs for poor and middleincome countries.
  - Infographic link:
     <a href="https://presentations.gilead.com/files/2017/2181/2794/Bekker\_Summary\_AIDS2024">https://presentations.gilead.com/files/2017/2181/2794/Bekker\_Summary\_AIDS2024</a>
     PURPOSE1 24Jul24.pdf
- New support group for women that want to breastfeed in South Africa.
- How HIV reservoirs hide in the gut and lymph nodes.
- How to communicate about HIV in the media.
- Marc Franke: Achieved remission from HIV after receiving a stem cell transplant to treat his leukemia.
  - Link to his story: <a href="https://linktr.ee/marc dp">https://linktr.ee/marc dp</a>
- How different generations affected by HIV can work together and learn from each other.
- Artificial intelligence in HIV.

## • CAB NEWSLETTER

Mandy mentioned that the theme of the newsletter is "Trust".

- What does trust mean to you?
- How to build trust?
- How to build trust in a community?

Due date for submissions – August 13. Submissions can include poems, recipes, stories, photos, etc. For accessing previous CAB Newsletters, please login to the PHACS website, go to CAB > <u>CAB Semi-Annual Newsletter</u>

Kim suggested photos of trust falls from coordinators at the sites.

#### LAY SUMMARIES

**Mandy** talked about the designed lay summaries. The publications committee chose five lay summaries to be designed this year. Sam designed one lay summary as an animation. Mandy is designing the lay summaries as infographics.

- 1. Studying the use of ARTs and hypertensive disorders in pregnant people living with HIV.
  - a. **Kim** suggested adding a link for more information about the lay summary.
    - Mandy noted that she will explore the possibility of adding a QR code with a link to the publication.
  - b. **Sannita** mentioned that the information presented is very important.
  - c. **Carol** suggested that the text should be bigger.
- 2. Studying weight gain during pregnancy for persons living with HIV in the United States.
  - a. Kim suggested adding stretch marks. It's a great resource for everyone. Adding a QR code will allow everyone to learn more about this topic and avoid sharing misinformation.
    - i. Sannita agreed that it is a great education resource for participants.
  - b. Carol suggested making words bolder and brighter.

Next steps for these lay summaries are:

- Adding suggestions from CAB members
- Editorial review
- Community Task Force review
- Review from the authors
- Dissemination (post on PHACS website and Project Positive website)

If anyone would like to view previous lay summaries, those can be found on the PHACS website under Findings > Research summaries.

### PROJECT POSITIVE LAUNCH BRAINSTORM

**Mandy** talked about Project Positive website. The HECC is planning to schedule the official launch at the end of summer (end of August-early September). She mentioned that the website will be mobile phone friendly at that time. She asked the CAB members for activities for the launch. Some activities suggested were:

- Virtual bingo
- Word search
- Jeopardy game

If anyone has other ideas for the official launch, please contact Mandy (aflores@hsph.harvard.edu).

**Gena** asked about the possibility of having a meeting with community members to explain PHACS committees and working groups or developing a resource (e.g., infographic) for participants. **Mandy** said that the suggestion will be discussed in the HECC.

NOTE: The next CAB call will be on August 22, 2024, at 12:00 PM ET.