CAB Conference Call January 26, 2023 12:00 ET Meeting Minutes

Participants:

Carol Chitara Claire	Bronx-Lebanon Hospital Center Ann & Robert H. Lurie Children's Hospital Harvard T.H. Chan School of Public Health
Eduardo	Harvard T.H. Chan School of Public Health
Falon	University of Colorado, Denver
Gena	University of Miami
Jackie	Westat
Karim	Westat
Kylie	Texas Children's Hospital
Lesley	Texas Children's Hospital
Mandy	Harvard T.H. Chan School of Public Health
Morganne	FSTRF
Raiko	University of Colorado, Denver
Rosalva	University of California San Diego
Theresa	Texas Children's Hospital
Trinise	Tulane University

• APPROVAL OF MINUTES

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

• SELF-CARE SPACE

Eduardo led the self-care space.

• ICEBREAKER

Mandy led the icebreaker.

• INTERNATIONAL COLABORATIONS

Healthtalk.com

Mandy talked about the website. The website shows the experience of participants living with a health condition. The stories can be watched, listened to, or read. For some stories, actors were hired to share the stories. Mandy and Claire met with the researchers (Bakita and Tanvi). It is possible that both researchers will travel to Boston next month. **Mandy** mentioned that this will be a great opportunity to talk with them about their work. She asked the CAB members what topics should be discussed with them. In addition, **Claire** asked which topics could be included in a website.

• **Chitara** suggested asking them how they encouraged participants to share their stories on the website.

- **Lesley** pointed out that it is very important to compensate adequately when participants share their stories.
 - **Claire** agreed with Lesley. She mentioned that we should think about ways to avoid being coercive. It is a fine line between compensating people and not feeling obligated to participate.
- Rosalva talked about the shortage of baby formula that they were experiencing in her city. At
 her site, doctors and social workers were looking for ways to provide the formula to newly
 diagnosed moms. She wondered if in the UK they were providing the formula to people living
 with HIV.
 - **Mandy** agreed that the decision between formula and breastfeeding could be influenced by availability and/or financial reasons.

German Centre on Child and Adolescent Health

Claire presented the HECC's community engagement work to German researchers and clinicians. She talked about strategies that have work for community engagement:

- 1:1 interactions.
- Flexible participation.
- Include participants 16 yrs. old+ in groups.
- Dedicated staff.

In addition, she presented lessons learned:

- Not emphasizing expertise.
- Building trusting relationships with community members.
 - Important to acknowledge each participant as a whole person.
- Asking for community input in all the stages of a project (from beginning to the end).

Spanish speaking CAB Update

Eduardo provided an update about the national Spanish-speaking CAB. The group is still collecting information from sites about potential Spanish-speaking participants. Then, there will be a meeting with PHACS leadership to present the information that was gathered from sites.

NOTE: The next CAB call will be on February 23, 2023 at 12:00 PM ET.