CAB Conference Call August 27, 2020 12:00 EST Meeting Minutes

Participants:

Carrie University of Colorado, Denver

Claire Harvard University
Deontay University of Miami

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Juanita Tulane University

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

Megan Westat

Paige University of Alabama, Birmingham

Sannita University of Miami Trinise Tulane University

Veronica University of California, San Diego

APPROVAL OF MINUTES

The minutes from the August 27, 2020 call were approved with no changes.

PARALLELS BETWEEN COVID-19 AND HIV

Claire talked about the parallels between COVID-19 and HIV. The CAB has been talking about these issues since the start of the pandemic. The Health Education and Communication Committee (HECC) is interested in talking to the CAB about the next steps. There have been several nice viewpoint articles in the news recently. One was written by two young people who grew up with HIV. There was another about advocating for the community's purpose in research. These articles were published in academic journals. There may be other places to share these reflections.

Claire encouraged the CAB to think about whether they would like to publish anything about this topic. The HECC can support the CAB in whatever decision they make. The HECC could also help put together a writing team to author a paper.

Claire reviewed some of the prior feedback from the PUG. The PUG had talked about how HIV and COVID-19 had been attached to certain groups of people and stigmatized. The PUG also talked about how HIV and COVID-19 have disproportionately affected communities of color. The PUG mentioned that there was misinformation about the medicines that could be used for HIV and COVID-19. They also talked about stigma around HIV and COVID-19. There may also be similarities in terms of invincibility. Some people think it cannot happen to them. There has also been fear and misinformation. The PUG thought there may be a perception that COVID-19 is seen as more important that HIV. This could be because some celebrities have reported getting COVID-19 first. One of the PUG members felt that growing up with HIV gives them a higher tolerance for uncertainty in the world like COVID-19. Finally, the PUG talked about life with HIV and COVID-19. Both can represent a new normal.

Claire reviewed some of the prior feedback from the CAB. The CAB talked about worrying that people living with HIV could be at a higher risk for getting COVID-19. The CAB also talked about similarities in

stigma. Some CAB members talked about doctors taking precautions. Some of this has been triggering to some people. This is because it would remind them of stigmatization in health care such as doctors wearing two gloves around people living with HIV. Many CAB members also talked about mental health outcomes. There had also been discussion about advocacy. The CAB previously talked about HIV and COVID-19 in communities of color. Communities of color have been more likely to get COVID-19 due to higher exposure. They are also more likely to have worse health outcomes. This is due to structural and institutional racism.

Claire asked the CAB about next steps. **Trinise** talked about parallels. It would be helpful to talk about the learning process. CAB members could talk about what they have learned from the start of the pandemic through now. This could be especially helpful for people living with HIV.

Trinise talked about testing. CAB members may be interested in talking how it feels to be tested for COVID-19. This includes information about standing in line, waiting for results, and/or getting a positive result. CAB members might also want to talk about how a vaccine will be received. Some people may feel the vaccine is rushed. For people living with HIV, this could be especially concerning. They may not feel it is safe. People living with HIV might want to know the vaccine has been researched in the HIV community.

Veronica talked about COVID-19 research at the University of California, San Diego. There is a vaccine trial enrolling people living with HIV.

Liz talked about the role of CABs and how important they have been in the HIV epidemic. The role of CABs originated in the field of HIV. Advocacy has been so important.

Trinise talked about advocacy opportunities. Since the start of the pandemic, it has been difficult for advocates to meet together. **Trinise** explained that her site is doing clinical work, but has not been able to do advocacy work. Many places have been closed down. It can be tough for people to learn the technology of virtual meetings. **Claire** thanked **Trinise** for sharing, and encouraged **Trinise** and other CAB peer navigators to think about sharing about their experiences with their patients and issues with access to care. **Trinise** explained that many people living with HIV might have difficulty getting medical appointments because clinics are so busy with COVID-19 patients. Some people might not want to leave their house. Some people may be afraid to disclose that they had COVID-19. Due to this stigma, some people have lost their lives.

Claire encouraged the CAB to think about these parallels further, if desired. CAB members can submit feedback through the survey.

PHACS 2020 TRANSITION

Megan talked about the PHACS 2020 transition. **Megan** reviewed the information that **Dr. Ellen Chadwick** talked about on the last CAB call. PHACS 2020 is the next round of funding for all of PHACS. During the last call, many CAB members expressed concern about site re-competition. **Megan** talked about site re-competition. In PHACS 2020, the NIH wants to make sure PHACS runs as smoothly as possible. This means they want confirmation that every site is doing the best work possible. In order to get that confirmation, all sites will have to "compete" to show that they should continue to work on PHACS. There is a possibility that some sites will not be able to continue next year. It is also possible that all sites will be able to continue. The re-competition will not happen until next year.

Many CAB members previously expressed a desire to advocate to the NIH. The CAB wants to tell the NIH about their concerns about re-competition. **Megan** and **Claire** proposed that the CAB consider putting together a letter and multimedia package. A letter of non-support could be written on behalf of the CAB. Additionally, a package of video clips, audio clips, and/or written articles could accompany the letter. This way, the letter and package could be circulated to as many people as possible and the CAB voices could be heard. After the package is sent out, the CAB could invite an NIH representative to a CAB call to follow up.

The CAB approved the idea. **Megan** invited CAB members to volunteer to be part of a task force for the package. CAB members can volunteer or share ideas through the survey. The CAB will talk about this idea further on the next CAB call.

NOTE: The next CAB call will be on Thursday, September 24, 2020 at 12:00 pm EST.