African American Health Coalition  
March 10, 2022

Attendance:
Yvette Conyers (Chair), Sebrone Johnson (Co-Chair), Melanie Funchess, Carl Scott, Adeanna Tazell, Anne Kern, Asim Johnson, Candice Lucas, Claudia Burcke (Wilmot), Cynthia Adell, Don Amrstrong, Rashid Muhammad, Florence Dukes, Gina Cuyler, , Jayslynn Antonetti, Joseph Searles, Juireith Donko-Hanson, Kathleen Maignan, Kathleen Mcgrail, Lydia Alston-Murphy, Laura Sugarwala, Mechelle Sanders, Melissa Loh, Natalie LeBlanc, Nikesha Gilmore, Patricia Terziani, Sadandaula Rose Muheriwa, Sparkle Wells, Van Smith, Gail Berkes, Florence Dukes, Brooks Benton, Asim Johnson, Laura Sugarwala, Martha Hope, Mechelle Sanders, 

Staff: Jeff Freeman, Linda Clark, Jonathan Ghent, Sarah Farash, Holly Sienkiewicz, Phyllis Jackson

Data Presentation (Jeff Freeman: Kidney disease presentation).

Linda to send Hidden In Plain Sight – NEJM article to AAHC

Wilmot Cancer presentation (Dr. Candice Lucas):

Discussed the journey for Wilmot Cancer Center to reach a designation requiring 5 years (NCI Designation). Currently the closest is at Roswell. Using cancer system visual analytic system (CANVAS) defined catchment areas – 27 counties, 29% rural – 3 million residents.

The COE Team (Community Outreach and Engagement)


Discussed why there is a need for community engagement. There were several thoughts from the coalitions:

- To make sure that the services are going to the community
- nothing about without me
- Develop trust and transparency with residents
- A collaboration relationship between science and community (lived experience)
- Education and Empowerment of communities
- Social determinants of health are just as impactful on outcomes
- to see the community's assessment of themselves, and see what they want/ need
- When you involve people in the conversation there is more follow through on their part

COE partners with several community connections through CCAC (Cancer Community Action Council), CABs and coalitions, integrates community engagement throughout Wilmot research and clinical programs, and partner with community for outreach, education and research.

Hoping to grow CCAC from 54 to 100 – 46 CBOs, 23 counties.
Four working groups

Working on Educational series – Community Conversations on Cancer – match

Discussed smoking rates from 2018 and noted how much higher for Blacks compared to US rates (source)

From the chat:

- Consultations on cancer-relevant grant applications;
  Reports on demographics, cancer risk factors, and cancer incidence and mortality for the Wilmot catchment area;
  Reviews of cancer research studies through ad hoc committees of community members
  Assistance with translation of study materials (e.g., consent, questionnaires) into Spanish
  To request any of our services, please use this form: https://redcap.urmc.rochester.edu/redcap/surveys/?s=NFCNXLYTM7
- AAHC encouraged to join the CCAC.

Rose Muheriwa Presentation –

Introduced herself – midwife and educator. She has interest in counseling and sexuality – interest in early life experiences and sexual behaviors. She has a proposed study. She is from Malawi. Many young people having children young. Many living with HIV. Multiple sexual partners and the nature of relationships. She looked at data here as a postdoc.

- Adolescent boys initiated sex more
- Black or African Americans have the highest percentages of early sexual initiation
- 7% initiated sex before 13 years
- 10% had four or more sexual partners in their lifetime
- Condom – 49% females and 6% of boys used with first
- Some national data was presented (Michelle et al, 2022)

Proposed Study to understand experiences that support the sexual health development of young Black and Latino adolescents and determine whether conducting research with young adolescents in Rochester is socially and technically feasible. She discussed specific aims of the study. Will do a qualitative study – focus groups. Specific question areas discussed for each subgroup:

- Community stakeholder discussion –
- Parents and primary caregivers
- Boys and girls 10-14 years old

Specific Questions for the Coalition were reviewed (see slides)

Center for Youth, Planned Parenthood, R-Centers, Hillside, Baden Street, Center for Youth, Villa of Hope, Teen Empowerment, Urban League, Action for A Better Community
Linda will help with a survey to see if the coalition wants to provide a letter of support.

**My Health Story (HS and SF)**

- Attempt to get health outcome data and SDOH
- The first survey launched in 2018
- Refining and updating questions
- Reviewed categories of questions asked.
- Pregnancy experience – undergoing revisions – right now last version did not garner a lot of good information as it was.
- Children’s health also hard to determine
- Survey had multi-channel outreach to generate broad survey input.
- Input and Feedback to provide input on:
  - Survey questions
  - Recruitment strategies and data collection efforts
  - Dissemination of findings and reports
- We will have a 2nd draft that we can send to entire coalition for review – by March 18th
  - Understand priorities and needs of the coalitions
  - Will work with ambassadors / Jackie Dozier
  - Increased participation outside of Monroe County
- Noted the need to partner with other organizations to collaborate whenever possible
- Volunteers to review with the volunteer group
  - Dr. Yvette Conyers
  - Jayslynn Antonetti
  - Melanie Funchess
  - Asim Johnson
  - Dr. Candice Lucas

**Announcements:**

- Fidelis is having an Easter event – 1 pm to 3:30 pm
- Dr. LeBlanc will e-mail information
- RATFA testing event for National HIV testing Day – looking for vendors – date not set
- COE / Wilmot – grant to study yoga as a pain intervention for Black cancer patients – looking for a Faith and Church Advisory Board – looking for feedback
- Don’t forget the Colon at the mall.