

Research & Evaluation Committee

MEETING SUMMARY

Monday, November 18, 2019, 10AM-12PM
 Willing Heart Community Center
 555 Martin Luther King Blvd. Newark, NJ 07102

PRESENT	EXCUSED	UNEXCUSED
1. Ann Bagchi, Ph.D. (Chair) 2. Summer Brown (Secretary) 3. Kasny Damas 4. Travis Love 5. Debbie Mohammed 6. Warren Poole 7. Sharon Postel (Non-Voting)	8. Natalie Brown-Muhammad 9. Corey DeStefano (Vice-Chair) 10. Karen Ehiri (Non-Voting) 11. Patricia Moore 12. Providencia Rodriguez	

Guests:

Staff: Tania Guaman, Vicky Saguy

1. Welcome and Moment of Silence

Ann Bagchi (Chair of the Research and Evaluation Committee) called this meeting to order at 10:14AM. A moment of silence was observed for all those living with, those who are affected by, and for those who have passed from HIV/AIDS.

2. Roll Call

Tania Guaman (Support Staff) conducted the roll call. Quorum was established later during the meeting.

3. Public Testimony

There was no public testimony at this meeting.

4. Review Action Steps

Action Steps	Responsible Party
1. Present the Behavioral Health Cascade	Sharon Postel
2. Update Workplan/Calendar	Support Staff

Ann Bagchi (REC Chair) reviewed the Action Steps. The Behavioral Health Cascade will be reviewed later in the meeting.

5. Approval of the Meeting Summaries from September 16 and October 21, 2019

The September 16th Meeting summary was reviewed at the last meeting. Ann Bagchi, Ph.D., REC Chair, asked for a motion to approve the Meeting Summary. Debbie Mohammed motioned to approve. Kasny Damas seconded the motion. All members agreed. There were no oppositions or abstentions.

The October 21st Meeting summary was reviewed. Ann Bagchi, Ph.D. (REC Chair) asked for a motion to approve the Meeting Summary. Kasny Damas motioned to approve. Warren Poole seconded the motion. All members agreed. There were no oppositions or abstentions.

Tania Guaman (Support Staff) asked committee members if the length of the Meeting Summaries should be shortened since support staff noticed summaries are lengthy sometimes. Sharon Postel (Consultant) mentioned that the summaries should continue as they are because the amount of detail reminds members of what was discussed. Warren Poole added that the summaries are very detailed and may answer questions a reader might have. Ann Bagchi, Ph.D. (REC Chair) added that it is convenient to have a detailed accounting. The summary shared at the Planning Council Meeting can provide a high-level overview; Planning Council members can review the more detailed notes if they wish. Sharon Postel (Consultant) agreed with REC Chair and added that people can look at committee reports if they have any questions.

6. Updates from other Committees

- **COC:** Tania Guaman (Support Staff) provided the report.
 - o No meeting was held in November.
 - o The COC is waiting for guidance from the Recipient on the new format for the Standards of Care. The COC will probably start the new format with Housing, as previously discussed at the Planning Council Meeting.

The next COC meeting will be held on December 12, 2019 at the Willing Heart Community Center located at 555 Martin Luther King Jr. Blvd. Newark, NJ 07102.

- **CPC:** Tania Guaman (Support Staff) provided the report. The last Comprehensive Planning Committee meeting was held on Thursday, November 8, 2019 at the Willing Heart Community Center in Newark. The following occurred at the meeting:
 - o The Committee reviewed the Integrated Health Prevention and Care Plan Progress Report. Sharon created and provided an overview of the Progress Report. Members identified areas of improvement and target populations.
 - o The CPC updated the Integrated Health Prevention and Care Plan Goals. The CPC will continue to update the objectives at the next meeting.

The next CPC meeting will be held on December 13, 2019 at the Willing Heart Community Center located at 555 Martin Luther King Jr. Blvd. Newark, NJ 07102.

- **CIA/CC:** Tania Guaman (Support Staff) provided the report. The last Committee Involvement Activities Committee meeting was held on October 23, 2019 at the Willing Heart Community Center in Newark. The following occurred at the meeting:
 - o Participants discussed questions about housing and barriers of not having housing. The following were some of the points raised at the meeting:
 - "If I do not have housing, I am not going to worry about my medication."
 - The new requirement from the City of Newark to do a drug test (blood or urine) in order to receive housing has not been confirmed. We are still waiting on the Recipient's guidance about this issue.
 - Participants mentioned barriers to Viral Load Suppression. Some of the answers included housing, transportation, forgetting to take medication, and taking the medication reminds you of living with HIV and the trauma associated with it.

- A Presentation about the Ending the Epidemic Plan will be provided at the next CIA Meeting. The presentation will be prepared by Support Staff, based on EtE meeting with the State.

The next CIA meeting will be held on November 20, 2019, at 5 PM at the Willing Heart Community Center located at 555 Martin Luther King Jr. Blvd. Newark, NJ 07102.

Sharon Postel (Consultant) asked for the CIA summary to be provided to include the findings in the EtE Plan, including questions and the consumers' input.

7. Old Business

There was no Old Business discussed at this meeting.

8. New Business

- **Presentation: Consumer-Based Participatory Research**

Ann Bagchi, PhD. (REC Chair) provided the presentation. A lot of the work done by the Committees and Planning Council involves consumer input. There are efforts to get people more involved in research, including those of the NEMA committees and Planning Council. One problem frequently mentioned relating to such research projects is that consumers might feel used and that they are not getting anything back in return. The main idea of a Consumer-Based Participatory Research (CBPR) is a partnership.

- A Consumer-Based Participatory Research is not a specific research method but a research approach that shows commitment to working directly with members of the community. It is sharing power and engaging community partners. It provides immediate benefits the communities involved. The Newark EMA already uses this research approach to some extent.

Sharon Postel (Consultant) asked: "What kind of direct benefits are typical in Community-Based Research?" Ann Bagchi, Ph.D. (REC Chair) mentioned that giving direct feedback and allowing community members to look at the study's results and act on them is one way of giving back. Bagchi provided two examples from the Stigma Reduction Workshops she led at NJCRI several years ago. Before the first meeting, participants completed questionnaires that included the Berger Stigma Scale. At the second meeting, participants were able to review the aggregated data from the surveys to identify the most common types of stigma reported. This helped participants see that others share their experiences with stigma. The participants in the workshop also used information from the workshops to develop, organize, and conduct a health fair as a Stigma intervention. Community members (NJCRI staff and consumers) worked together to develop this intervention. Sharon Postel (Consultant) asked: "Is there some way to state the benefits of helping in a survey at the beginning of the survey to avoid consumers thinking they are being used? Or to design the survey so consumers get something back?" Bagchi mentioned that the idea of this type of research is to work openly and collaboratively with community members so that the benefits are clear from the onset.

- The goals of CBPR are to increase the knowledge of a particular phenomenon, integrate knowledge with policy, and create social change. Its goal is to improve the health and quality of life of community members.
- It is one of the 8 areas of critical importance to public health education since 2003, according to the Institute of Medicine.
- There are 9 Guiding Principles – For instance, disseminating the results to people in the community and not only on peer-review publications or NEMA leadership. Also, getting the people in the study to distribute the results. For example, NEMA could do studies and the agencies may or may not distribute them, but a part of the goal should be to have a broader dissemination to benefit the community at large.
- *Community as Unit of Identity*
Units of Identity are socially created entities in which people have membership. They are created and re-created through social interactions. Everything in our world is socially determined. They can be geographical bound (e.g., neighborhoods or in NEMA service area) or dispersed but sharing a common interest (e.g., gay, bisexual, and men who have sex with men).
- *Core Components/Phases in Conducting a CBPR*
CBPR follows a cyclical process with seven components. Several of these mirror activities already being undertaken within NEMA. The first steps in CBPR are to form partnerships (e.g., NEMA) and assess the community strengths and dynamics (e.g., NEMA's Needs Assessment). Based on the Needs Assessment, the team identifies priority public health issues and research questions (e.g., Priority Setting Allocation and Needs Assessment). Once priorities have been identified, the team designs and conducts the intervention or research. Community members are directly involved in the process of providing feedback and interpretation of the research findings (e.g., Presentations to different committees to get feedback and make revisions). The final step is disseminating and translating project findings. Within NEMA, information gets disseminated to all committees and is integrated into processes, but not all agencies disseminate this information to their clients in ways that are meaningful to them. Most clients are not going to read research or committee reports. Maintaining and sustaining the partnerships are the center of the CBPR.
- CBPR and Health Inequalities: A main goal of CBPR is to address health inequalities by understanding the historical and contemporary social, economic, and environmental context in which inequalities originate.
- Following the presentation, the committed discussed the following questions:
 - How does NEMA currently implement CBPR-Type approaches to research?
 - What are the challenges to greater community involvement?
 - How can research findings be better disseminated to the community?

Bagchi (REC Chair) questioned whether incentives given to participate in research studies is sufficient for giving back to the community. Sharon Postel (Consultant) mentioned that what the research is about, expectation from participants, and the give back to the community should be stated up front. Postel also mentioned that the NEMA website in development and could be used to disseminate information to the community. Postel added that a one-pager with key findings could be used to identify what was done, what was found, and what will be done afterwards. Postel also mentioned that a Research project should define health inequities, the benefit to the community, and how they will be addressed and reduced after the study is completed.

Bagchi (mentioned that dissemination is an issue, since it is not known if people would know where to find the reports or if they understand the reports. Bagchi also mentioned that the EtE report was not easy to read and what is given to the community must be easy to follow. She added that the information given back to the community should include what they want to know, what they need, and the information that can help them. Postel commented that consumers could be asked how and when they want to see the results. Bagchi mentioned that this question could be added to the 2020 Needs Assessment.

Sharon Postel (Consultant) added that there is a big emphasis on providing stable housing on the next Needs Assessment as part of the End the Epidemic Initiative. Debbie Mohammed mentioned that Luis Ulerio, Director of St. Claire's Housing Program, should join the committee's conversation when housing issues are going to be addressed.

Additional discussion questions:

- What are the assumptions being made about how "community" is defined? Ann Bagchi, Ph.D. (REC Chair) mentioned that Community is defined as people Living with HIV/AIDS. Yet, she added that, due to stigma, people generally do not want to be defined as members of that community stigma, thus they might not want to be part of the research. Another question might be to ask people to define their own community. Tania Guaman (Support Staff) mentioned that other HIV Planning Councils redefine the community and do not use the word "consumers" to refer to PLWHA. They use the term '*People Affected by HIV*'.
- What more could be done to foster more meaningful partnerships? NEMA has meaningful partnerships with agencies but need people living with HIV more involved.

Sharon Postel (Consultant) recommended that the CBPR Presentation be given to the Planning Council, which is required to have 4 presentations per year. Warren Poole mentioned that a HOPWA presentation could also be given at the Planning Council since not everyone is aware of all the benefits people can receive from HOPWA. Poole mentioned that HOPWA has sub-programs that people may qualify for; HOPWA can freeze its benefits instead of terminating people from the program. Bagchi, mentioned that this presentation could be given at the Continuum of Care Committee.

- Discuss training needs for FY 2020.
Ann Bagchi, Ph.D. (REC Chair) proposed the following training topics:
 - Methods of dissemination to the community – Include the questions previously discussed about dissemination at the CQI Committee Questionnaire and the information gathered to talk about what the community needs are.
 - Bagchi will do some research to find creative dissemination methods from prior CBPR studies.

Kasny Damas proposed that a CBPR study include secondary data analysis in the CQI Committee questionnaire since the questionnaire is done yearly and the data are collected within a one-month period. Damas indicated that the following questions could be sent out to the agencies:

- How do they obtain the information regarding the EMA? What is the best method for them to obtain that information? Where do you get the information regarding HIV?

- What information do you want or need that you are not finding from the EMA?
- How would they prefer to receive data?

Damas stated that Karen Ehiri can help disseminate this questionnaire to all Case Managers and send back the results. Warren Poole asked if these questions could be asked at the CIA meeting on Wednesday. Damas replied this could be asked at the next meeting or any other meeting. Travis Love mentioned that these questions could be also asked from providers too.

2019 Behavioral Health Cascade: Sharon Postel (Consultant) gave an overview of the findings. Postel mentioned that there are 6 measures of Behavioral Health. Postel also mentioned that there was a Behavioral Health Integration Project Committee Meeting on October 3rd and these measures were clarified to all attendees.

- 1) BHIP1: PLWH Screened for Depression using an evidence (Based on NQF 418)—
Using an Evidence-based tool PHQ9 and PHQ2 with Patients screened for clinic depression as numerator and patients 18 or over who had had one or more primary medical care visit as denominator. If the patient has not had a primary care visit, then the patient is not included in this data or in BHIP2. If the patient screened positive, then there was not a referral plan.
- 2) BHIP2: PLWH Screened for Substance Use Disorders (Based on NQF 418)
- 3) BHIP 3: PLWH with Positive Screens who have follow up Plans (Based on NQF 418)
If screened positive, then patients must have a follow up plan.
- 4) BHIP 4: PLWH with BH Disorders Retained in BH Care (Not an NQF Measure)
If a behavioral diagnosis is given, then you are retained in Behavioral Health Care. A mental or substance use provider must report back that information, which might present a gap.
- 5) BHIP 5: PLWH with BH Disorders Viral Suppression (Based on NQF 418)
- 6) PLWH with Viral Suppression (NQF 2082) (Collected through NJ CPC)

Findings included:

- 91.7% of PLWH were screened for depression and 92.9% of PLWH were screened for Substance Use. Warren Poole mentioned that the reason not everyone was screened could be that the person is in denial and might not complete the screening. Debbie Mohammed mentioned that this could be in part that it reflects patients who are screened and receive care. Mohammed also mentioned that she screens patients and have seen an increase use of cocaine than heroin.
- 39.0% of PLWH who screened positive have follow ups and 28.9% of PLWH with BH Disorders are retained in BH Care. The data is computed from the surveys received and the main service for this category is Psychiatric instead of Individual Counseling. Sharon Postel (Consultant) clarified that this excluded people who have individual counseling and people who have not had a primary medical care visit. More research on this was suggested by the Consultant. Postel added that the Retained in care measure could change because the behavioral disorder has to be populated.
- The Viral Load Suppression measure is 84.0% for PLWH with BH disorders and 85% for PLWH in general. This measure does not change since they are receiving medical care. Ann Bagchi, Ph.D. (REC Chair) asked about the viral load suppression of those who screened positive but were not referred. Postel (Consultant) explained that if the patient is receiving medical care, their viral load seems to be low despite any other issues they might have. Bagchi asked if this information would be included in the Final Needs Assessment. Postel confirmed that this information would be included. Postel (Consultant) added that another meeting will be held this week about the BHIP measures and that all the services received would be included

in the final report. Ann Bagchi (REC Chair) asked if the comparison between Non-BHIP and BHIP agencies would also be included. Postel (Consultant) stated that it would be included, and that the information shows a minimal difference between the measures of the Non-BHIP and BHIP agencies. Tania Guaman (Support Staff) asked about the next steps of the 2019 Needs Assessment and the expected completion date. Postel (Consultant) mentioned that the next step is to put the three parts together which will be complete before Thanksgiving.

9. Administrative Issues

Ann Bagchi, Ph.D. (REC Chair) asked Staff to talk about the plan for future meeting locations. Tania Guaman (Support Staff) commented that the meetings will continue to be held at the Willing Heart Community Center. Staff also mentioned that the facility provided a discount on rental fees starting this month because support staff found a different place for \$900 and this facility matched the price. Warren Poole asked if the rate would decrease if any meeting is cancelled. Support Staff confirmed that credit will be awarded if meetings get cancelled. Support Staff also mentioned that there will be construction in the next couple of months and future meetings will be held at the Sanctuary.

- ***REC Membership - New member vote***

Tania Guaman (Support Staff) mentioned that Karen Ehiri's membership had to be re-voted because there was no quorum at the last meeting. Ann Bagchi (REC Chair) asked for a motion to accept Karen Ehiri as an Official Non-Voting Member of the REC. Warren Poole motioned to accept. Kasny Damas seconded the motion. There were no oppositions or abstentions.

- ***Meeting Evaluations & Member Attendance***

Tania Guaman (Support Staff) reminded all REC members to complete the meeting evaluations. Prior evaluations mentioned a recommendation for discussions of Telemedicine. Ann Bagchi, Ph.D. (REC Chair) mentioned that the Telehealth Needs Assessment will be done soon, and preliminary data will be available. Bagchi, Ph.D. suggested that she could provide a presentation next year to share the findings.

Tania Guaman also mentioned that there was a recommendation to have a presentation on Descovy. Poole shared that this is the new PrEP medication from Gilead, replacing Truvada. It was also mentioned that this medication does not have the long-term side effects of joint/bone and kidney problems. It was asked if any patients had had prior authorization issues with this medication. Warren Poole mentioned that so far no issues have been noted. Travis Love mentioned that this medication is not for cisgender women and transgender men since these populations were not included in the research study. Travis Love mentioned that women were also not included in the study.

Tania Guaman (Support Staff) mentioned that calendar invites are being sent to track attendance and asked that members accept the invitation. Bagchi, Ph.D. asked all members to respond.

10. Announcements

Warren Poole announced the following:

- Thanked all that donated for the Holiday Party and asked those who have not already done so to donate.
- The World AIDS Day Event for Peter Ho will be shared. One sheet is the flyer and the other is a confirmation of attendance.
- The CIA will continue to get consumers involved in the CIA and Planning Council

Travis Love announced the following:

- Transgender Awareness Week: There will be a Mascara Event on Transgender issues and education. Breakfast and Lunch will be provided. The event will be held on Wed. 20th at 10 am.
- Come together Event on November 26. Rutgers Research will be talking about their current research. This event will be at the Medical Science Building in South Orange Ave. in Newark

Tania Guaman (Support Staff) announced the following:

- World AIDS Day events are being gathered by Support Staff and will sent via email all at once.
- PrEP Webinar- Gilead Donation of PrEP: Gilead will cover the cost of the PrEP medication and the Department of Health and Human Services will cover other costs. The program will start in December. DHHS asked to help share information about the program during World AIDS Day events. There will be a portal where providers can call or submit a form for patients who need PrEP. Summer Brown added that there are 3 requirements for the program: 1. PrEP Prescription, 2. lab test, and 3. no health Insurance for outpatient prescription drugs.

11. Next Meeting

The next REC meeting will be held on Monday, December 16, 2019 at 10AM at Willing Heart Community Center at 555 Martin Luther King Jr. Blvd. Newark, NJ 07102.

12. Adjournment

Ann Bagchi, Ph.D. REC Chair, asked for a motion to adjourn the meeting. Warren Poole motioned. All members agreed. The meeting was adjourned at 11:43AM.