



# Community Involvement Activities Committee

## MEETING SUMMARY

*The Planning Council believes that the voice of the community is paramount. The purpose of the CIAs is to help bridge the gap between the community and service providers by creating opportunities to involve community members in the planning process. In addition, community members will receive crucial updates on changes in the Ryan White and related health/social services.*

**Wednesday, March 24, 2021 from 5:05PM to 6:54PM**

Video-Conference via Zoom: <https://zoom.us/j/96635953539>

Teleconference: (929) 205-6099 / Meeting ID: 966 3595 3539#

**Attendees:** 18 persons were in attendance, including Poole and 3 providers. Two attendees were from Union County, 9 from Essex County, 1 from Jersey City, and 6 unknowns.

**Support Staff:** Tania Guaman and Vicky Saguy

**Guest Speaker:** N/A

### 1) Welcome and Moment of Silence

Warren Poole, Committee Chair, called the meeting to order at 5:05 PM and welcomed all in attendance. A moment of silence was observed for all those living with, those who have passed, and those affected by HIV/AIDS.

### 2) Mission statement & Ground rules

Poole stated the committee's mission statement.

### 3) Public Testimony

There was no public testimony.

### 4) Approval of the Meeting Summary from February 17, 2021

The February 17<sup>th</sup> meeting summary was sent electronically for review prior to the meeting. Poole asked for a motion to approve the meeting summary. One consumer motioned and another seconded. There were no abstentions or oppositions.

### 5) Ryan White Part A Updates

- Support Staff reported that HRSA announced that COVID-19 vaccine fees can be covered by Ryan White Part A, Ending the Epidemic, and FY 2020 Cares Act funds. This was followed up with a Conversation about the COVID-19 Vaccine.
  - One attendee shared that his insurance covered the COVID-19 vaccine. According to some attendees, some agencies ask for health insurance to get the vaccine while others do not. Consumers asked about who would benefit from the RW covering COVID-19 vaccine costs? Support Staff added that undocumented individuals or people who do not have health insurance can receive the vaccine through those funds.
  - Consumers shared that patients must make appointments to receive the COVID-19 vaccine for free at any Health Center. People from East Orange, Irvington, Newark, or Essex County can

register to get the vaccine through the Health Department. St. Michael Medical Center, Peter Ho Clinic is also giving free COVID-19 vaccines to its patients and allows those who are not patients to register too.

- Most people reported receiving at least one dose of the COVID-19 vaccine. Poole reported that there is no age limit now; anyone ages 16+ are now eligible to get the COVID-19 vaccine.
  - One attendee reported signing up for the COVID-19 vaccine online and has not heard news. Other attendees recommended to call agencies such as St. Michael or 110 William St. to schedule a COVID-19 vaccine appointment. Only 4 attendees reported having received the COVID-19 vaccine during the conversation.
- The Planning Council will use needs assessment survey data for the Priority Setting and Resource Allocation process. The Needs Assessment Survey collected telehealth data via online and paper surveys since in-person activities were not an option. One consumer reported doing 5 surveys for different agencies. Support Staff explained that the survey was anonymous, and all answers were captured.

## 6) Old Business

Needs Assessment Surveys: This item was discussed previously.

## 7) New Business

- Discuss consumer access to telehealth services during the COVID-19 pandemic. Poole reminded all attendees that answers will be recorded in the summary without names. Poole had a conversation with all the attendees using the following questions, and the answers were noted as follows:

### About Telehealth

1. If your health insurance plan would not cover telehealth sessions at 100%, would you still want to have virtual appointments? Why or why not?
  - "I don't like the telehealth whether through my insurance or not. I rather go to my doctor because I only see them every six months. If I had to do it every month, then I would like to the telehealth."
  - "I like to talk to my doctor face to face. On the phone is cool, but sometimes you have to be in the office, and you have to talk to the doctor. You just get a better vibe."
  - "I don't like telehealth. It is okay as a substitute if there is no other way, but I really prefer in person visits with my doctor. [In person] is more in depth and you get more accomplished that way."
  - "I rather be there, so I can ask them questions and see when they got your blood work [results] in front of you, and they explain every little detail. I am another one that [goes to the doctor] every six months... Now if it were something that had to be done every month then I wouldn't mind the telehealth, but I like the personal touch. [I] can build a connection between me and my doctor." The attendee added: "When it comes down to my doctor, I would rather do something personal. But I have been in Team Management's group on zoom and if that is considered telehealth, I love that because I can connect with people from different places like from Hackensack, Paterson, South Carolina, and Florida." For my mental health portion, I will do the telehealth. But when it comes down to my physical, I would rather be in front of a doctor talking to them, especially because I have a heart

condition and if I am doing telehealth, he is not going to be able to check my heart and let me know if everything is proper.”

- “I do not like telehealth. You cannot see the Dr. reaction and you can only hear a voice. It makes me go out. I am associating with my doctor and we have a good interaction. I really do not like telehealth, but I do not have any other choice.”
- “I like the one on one. I like to be there, so if they need to look at a certain spot, I am right there. I do not have to come in for another appointment because I too always get my appointments every six months. But if it comes down to telehealth I will deal with it.”
- “I do both. I do telehealth with 2 of my doctors and I do in-person visits with my other doctors. My telehealth visits are video so I can see them as I am seeing you. We do have the one-on-one and she can show me my tests results on the screen as she is talking to me. And for my other doctors that I go to the office. I like that also because you have the intimate relationship with them. I think it depends on the doctors and what you are going to see them for. I can see my primary [doctor] over telehealth, but I rather see my cancer and ID doctor in person. Both ways work for me.”
- Dr. Walter O. shared the provider’s point of view: this is a hybrid way to see your doctors. Patients can choose what they feel comfortable with. Telehealth could be for issues that are not that serious. For a routine checkup, every three or six months, the face-to-face visit would be better an in-person visit. A telehealth visit can be for follows up. In-person and telehealth services can be used to meet every patients’ needs.

2. Poole added that COVID-19 and telehealth services will continue to be part of the daily lives of everyone and stated that these questions are trying to find ways to make telehealth services better for the Ryan White community.

Are there ways to make telehealth better, more interactive more engaging? What are some of your concerns of participating in telehealth visits?

- An attendee referred to patients who need to talk to a person and cannot use telehealth services due to mental health conditions, such as substance abuse and mental health treatments where a patient may still need to come in for urine screenings.
- Consumers wanted resources for people who are not familiar with technology, who don’t have wi-fi or who do not know how to use technology. For instance, an attendee reported that the Ryan white program in Atlanta gave tablets to patients because of telehealth. Consumers recommend that classes are available to teach people how to be computer savvy, especially if they're going to be using either a telephone or a tablet.
- “I used telehealth. I enjoyed it. In some instances, I have preferred it but it's not a permanent fix”.
- You can talk telehealth, but if the doctor is not in on it, then it might not work for you” said another consumer who says “My doctor wanted me to do blood pressure tests myself during a certain period. I have the blood pressure machine and I have to bring the blood pressure and glucose machine to him for the results because he does not have the technology to get the reading from my machine. [Telehealth] needs some improvements”.
- A consumer mentioned that blood pressure machines can be prescribed by medical providers for people to do tests at home. An attendee mentioned that her machine has a memory card which can be inserted into a laptop to send the results to the doctor’s office.

- Poole added that the CIA will consider doing laptop or zoom trainings, as well as introductions on how to use blood pressure machines, digital thermometers, etc.

### **About COVID-19**

3. How do you feel about the way that your healthcare facility enforces COVID-19 safety practices?
  - Before the big COVID outbreak and when there was still COVID-19, I used to go to my doctor and they would wipe down everything after every person left the seat. The clinics protect their frontline workers and that is why they got the COVID-19 vaccine first.
  - I like the way clinic is set up. Everybody must come with an appointment. It is not congested. People cannot use the showers in the background. There is only have a certain amount of people in the chairs and you can only sit in certain chairs. I love the way UMD clinic is doing – in and out.
  - When I go to my doctor's office, they take my temperature at the door. I have to go to the office to do a urine test because of the medications I am taking. When I go to the bathroom, I do not know if they cleaned the bathrooms or chairs in the waiting area after patients used them. You must be cautious of surroundings and what you do when you go to the doctor's office.
  - My doctors' office is by appointments only. Only 5 people are allowed inside the office at a time. No walk-ins allowed. The office is only open for 4 hours a day and 4 days a week. The hospital custodians clean throughout the day.
  - I go to Rutgers. They are very efficient and do a very good job. I also go to a pain management clinic and they are extremely cautious. They have hand sanitizer at the counter which you must use when entering the building. If you use an ink pen, you take it from the clean ink pen and put it back in the used ink pen. If there is more than two people in the waiting area, the next person waits outside the office or in their car.
4. Have you or do you plan to get the COVID-19 vaccine? (Please share your experience)
  - "I received the first shot from my ID clinic. It was ok. I was not tired but my arm was sore." But the second vaccine hurt me, and I was sleeping the next day.
  - "I took the first shot and it made me drowsy. My arm was hurting, and I could not lay on my arm or my side."
  - "I took the first shot last week. It gave me the chills. I had to wait 30 minutes instead of 15 because of my allergy to shellfish... It made me tired. My arm was sore for a few days. I take the last one next month."
  - "I got one shot. No problem."
  - A provider reported having the shot on Monday. "I was fatigued, nauseous and had diarrhea. I just got one shot of Moderna. I had the shot at 11am and started experiencing the side effects by 3pm. The next day I was still tired, and I lost energy. They do a V-Safe tracking to monitor my symptoms."
  - "I got my shot last Friday and all I felt was a little pinch. I did not have any symptoms but I had Pfizer. A friend of mine had Moderna and her arm was sore.
  - Dr. Walter got the vaccine as well and stated that all the symptoms that everyone felt were expected and most common. The severity of the pain at the vaccination site depends on the experience of the person given the shot. If they do it very well, you just feel a little pain. Dr. Walter felt the pain at the vaccination site and after a couple of days it was gone.

5. For those who not gotten the vaccine, do you plan on getting? Why or why not?
  - An attendee stated that is planning on having the vaccine but is no register yet. They will register on Monday. "I have been just sitting back listening to the side effect people are having so far and I heard nothing serious, so I am going to take it now."
  - An attendee would like to take the one-shot, Johnson & Johnson but it is not available in most places yet.
  - According to the news, Johnson & Johnson is giving 70,000 vaccines to New Jersey.
  - Poole recommended to those who have not received the vaccine yet but would like to get it to check with providers about the vaccines, which one they are offering and ask them if the Johnson & Johnson will be available at their facilities. The Johnson & Johnson is available at University Hospital. To register, go to the website or call to verify.
  - Newark was giving Johnson & Johnson at the homeless housing and the YMCA. It was open to the public and do not need to live there.
  
6. What do you think can be done to help you access the COVID-19 vaccine for those who have the virus?
  - "I went through hoops trying to get this vaccine. I told them that I was diabetic, had asthma, was HIV positive, but because I wasn't 65 they rejected me." I registered with the state and no answer. They gave me a couple of places, but they do not answer their phone. Then place told me I had to be type one diabetes and not type two... "I guess because I am a long-time survivor and. My T cells are like 950 and I'm undetectable under 20 copies for over 10 years they don't consider me to be a risk factor."
  - An attendee mentioned that this is a personal issue and did not want to share.
  - All health care clinics should deliver the vaccine. I do not think I have to go all around downtown to get the vaccine. Three attendees agreed.
  - Ship out more vaccines.
  - "Other than putting in our drinking water, I do not think there is nothing else we can do."
  - I think your provider should be the one that offered to you or give it to you anytime that you can go and see your doctor. I think they should be pushing it more and more and more. We will never get a handle on this, if the right people don't have it to give it to their patients A lot of us are HIV positive, so our providers already know what our stats are so they could offer the vaccine to their patient, just like the flu shot.
  - I also think the pharmacist at the drugstore where the patient is picking up their medication should be in signing them up for vaccines. People can go to the Sam's Club in Secaucus to make an appointment to get the vaccine. Is Sam's Club, Walgreens and CVS is doing it how come Mike's and Nick's pharmacy and all small pharmacies are not offering it as well?
  - I go to the VA Hospital. I think it is good because I want to get my first my shot at the VA because they have my health record. I saw it on the news this morning that some small drug stores/pharmacies are receiving some vaccines in Newark.
  - An attendee stated called various sites within a 10-mile radius but most of them were out of stock and their line is busy when calling. Poole asked the attendee to give him a call before his next appointment at Peter Ho to register him for the vaccine with the clinic.
  - I think that it should come from your doctor.
  
7. Do think that your ID Doctor should be allowed to give consumers the vaccine considering consumers have a compromised immune system? (Verses having to register for an appointment and wait to be called in the shot)

Most attendees said yes during the previous question.

8. What is your opinion about the way things are opening in New Jersey? (Do you feel safe should the major restrictions stay in place and how long? Wearing mask, social distancing, etc) New Jersey is lifting some restriction such as social gathering, restaurants dining, and school re-openings in April or May.
- "I think that wearing masks should be mandatory for a little while. Social distancing should remain a little longer." I don't want to open up these all the way because New Jersey is one of the top states with COVID-19. "Just take it a little slower and don't rush. I believe the teacher should be vaccinated before the students are allowed to go to school. But wearing a masks and social distancing should continue to be mandatory.
  - Because students need to learn, the first priority are teachers. Students should be 6 feet apart and still wear a mask. They are coming with a new vaccine for children. Children should be vaccinated before going back to school, so they do not spread it. Restaurants should be open more than 25% since people need to make a living and a lot of restaurants are closed because they could not pay their employees and/or rent.
  - "I don't think they should let the kids go back to school until next school year in September." That is the reason why other countries have shot down again with the third wave because there is no vaccine for the children. My kids would still be done school via Zoom.
  - "If they want to go back to school, it depends on the parents and the teacher but I do not think they should be forced to go back to school."
  - I work in the school system and the parents had to do a survey to find out if their kids are going back to school. If they say their kids are not going back to school, their kids are not going back to school. Education is a must, and they are not learning through Zoom.
  - "We just have to take it slow. We just have to encourage people to get the vaccine and I think the agencies need to go back to work, because they get to relax at home. And as for the schools it is up to the parents. I believe we are going to wear masks, and social distancing for the rest of the year so we have to get used to it.
  - I think that because it is this late in the school year anyway I don't think the kids going back to school this year is going to help them any or at all with this year. Because it's such a touchy situation just let them stay out for the rest of the school year and if they're going to send it back let them go back in September and let it be a choice of whether they want to or not want to go.
  - The reason the kids are going to back to school is because they have to be promote them to the next grade and they do not want to promote them without letting go back to school. They are not going to fail any kids this year.
  - "A little bit of education is better than no education at all. Let them get out of the house and go back to school so at least they'll have some more foundation and get off to the zoom."
9. The Newark Eligible Metropolitan Area (NEMA) allocates the Ryan White Part A funds for five counties. The topic for the Needs Assessment this year was Telehealth. Should the Newark EMA push for more funding for telehealth visits or reallocate funds? (Reallocating of funds)
- Six attendees stated that "We should do both."
  - Funds are needed in both places.
  - Some doctors need to ask for more funds for telehealth.

- We need to put money into transportation like Lyft instead of bus since it is dangerous to travel in bus. Poole encourage this attendee to attend the next Planning Council meeting to provide a Public Testimony. The Planning Council meetings are the third Wednesday of the month.
- You have to spend at least 90% of the money to ask for money. I was part of the Jersey City Planning Council. You have a reason to ask for the money. Poole stated that because of COVID-19, the government is allowing to get more funding for certain services. There were funds from COVID-19 to cover for phone bills, house lines and rent through Emergency Financial Assistance.

**Important Information (Coming in the Near Future)**

1. Clinical trials looking at whether or not HIV medications can treat Covid-19
  2. Another trial looking at different drugs to treat Covid-19 for people with HIV
  3. Another trial will look at consumers who had Covid-19 and how they are managing life
- All three trials are probably looking for consumers to participate at some point. To learn more about clinical trials go to [clinicaltrials.gov](http://clinicaltrials.gov).

- Prepare to prioritize EMA services based on key priorities.  
Support Staff provided a brief presentation and a Priority Setting activity.
  - On a video, consumers made choices on how to prioritize the adding of Big rocks, little pebbles, and sand on a jar. In this example: the jar presents all the funds that the Newark EMA Ryan White Part A Program receives and has for the Core and Support Services. How would you fit all the Core and Support Services into the jar? Attendees mentioned that (Big Rocks) Core Services that need a lot of funds would go first, then (Little Pebbles) the Support Services that need a lot of funds and lastly the (Sand) Core and Support Services that needless funds.
  - Staff then provided a brief reminder that the Comprehensive Planning Committee (CPC) recommends the Priority Setting of HIV funds in the Newark EMA by asking other PC committees' input & recommendations for the PSRA process, reviewing data such as the Needs Assessment, Epidemiological Profile and other reports to put together the Priority Setting and Resource Allocation Report. The Planning Council reviews this report and the CPC recommendations and approves as present it or makes edits.
  - The CIA input also provides input on whether or not there is a need to apply for the Core Service Waiver, which allows the EMA to put more funds into support services. This was done during the December and January meeting. And it will be done again in 2021.

**10. Announcements**

Attendees participated in a raffle of 2 \$10 Walmart gift cards and a \$25 Applebee's gift card. At the next meeting, there will be a presentation about housing by the New Jersey Housing Collaborative.

**11. Next meeting**

The next CIA meeting will be held on Wednesday, April 28, 2021 at 5 PM via Zoom.

**12. Adjournment**

This meeting was adjourned at 6:54 pm.