Ryan White Part A Planning Council of the Philadelphia EMA Positive Committee Meeting Minutes April 10, 2017 12:00-2:00p.m.

Office of HIV Planning, 340 N. 12th Street, Suite 320, Philadelphia, PA 19107

Present: PH (20), PA (3)

Guests: Alex Shirreffs, Amy Cooper

Staff: Antonio Boone, Jennifer Hayes

Call to Order/Moment of Silence/Introductions: D. Gana called the meeting to order at 12:05p.m. He read the mission statement. A moment of silence followed. Those present then introduced themselves and participated in an icebreaker activity.

Approval of Agenda: A. Boone presented the agenda for approval. <u>Motion: G.T. moved, L.W. seconded to approve the agenda</u>. <u>Motion passed</u>: All in favor.

Approval of Minutes (*February 13, 2017*): A. Boone presented the minutes for approval. <u>Motion</u>: J.R. moved, L.W. seconded to approve the minutes. **Motion passed**: All in favor.

Report of Chair: None.

Report of Staff: A. Boone stated that the first integrated meeting of the RWPC and the HPG would happen next Thursday from 2-4pm. He explained that the integrated planning body would revise their bylaws and decide on a name. He added that priority setting was currently taking place, and allocations would be coming up in the summer. He stated that Jose Bauermeister would also be coming to present to the integrated body on Thursday.

A. Boone added that the consumer survey would be closing on April 16th. He encouraged the group to urge their acquaintances who received Ryan White services in Philadelphia, PA, and NJ to complete the survey. He noted that the survey was being promoted on social media with the hashtag #HIVTalkBack.

Special Presentation:

• HIV/HCV Presentation

A. Shirreffs stated that she'd been doing work around hepatitis at the Philadelphia Department of Public Health (PDPH) for 6 years. She stated that hepatitis C eradication was now possible. She noted that the federal government was interested in scaling up hepatitis C services, particularly for people who were co-infected with hepatitis C and HIV. She noted that the City recently received a grant focused on HCV eradication among people with HIV. She stated that medical case managers would be asked for feedback about the program.

Mission statement: The Positive Committee supports and enhances the role of people living with HIV/AIDS to empower their participation in the decision-making process of the Ryan White Part A Planning Council and the HIV Prevention Planning Group.

A. Shirreffs said she was joined today by Amy Cooper, who would be serving as a linkage coordinator in the program.

A. Shirreffs reviewed the epidemiology of hepatitis C. She said more than 4 million people in the US were estimated to have hepatitis C, and most of these people were undiagnosed. She said that hepatitis C was the most common reason for liver transplantation. She noted that hepatitis C was a more common cause of death than HIV. She said that there was more funding for HIV services than hepatitis C services.

A. Shirreffs presented a breakdown of people in Philadelphia who were estimated to have hepatitis C by year and age. She said that the CDC recommended that baby boomers, people who were between 45 and 64, be screened for hepatitis C. She stated that there was less knowledge of hepatitis C in these years. She noted that, in 2013, there was an increase in younger people who were getting hepatitis C, peaking in 2015. She stated that hepatitis C was common among injection drug users.

A. Shirreffs stated that surveillance of hepatitis C was being conducted by the PDPH. She noted that tattoos were a risk factor for hepatitis C. She added that incarceration could be a risk for hepatitis C through tattooing, drug use, and sex. She added that sex itself was also a risk factor.

A. Shirreffs displayed the hepatitis C cascade of care. She noted that the ultimate goal of the cascade was total eradication of hepatitis C. She noted that only half the people with hepatitis C in the US knew that they had it. She said that people with hepatitis C had to get a confirmatory RNA test after diagnosis, which few people got. She noted that 6% of people who were estimated to have hepatitis C were in medical care, and only 3% had been completely treated.

A. Shirreffs stated that an estimated 25% of people who were living with HIV also had hepatitis C. She said this rate ranged from 10-30% among MSM and up to 80-90% among people who injected drugs (PWID). She stated that HIV/HCV coinfection more than tripled the risk for liver disease, liver failure, and liver-related death. She noted that anti-retroviral therapy (ART) may slow the progression of liver disease by preserving or restoring immune function and reducing HIV-related immune activation and inflammation. She stated that anyone with HIV who had hepatitis C should be put on treatment for hepatitis C.

A. Shirreffs reviewed the prevalence rates of HIV/HCV coinfection in the Philadelphia EMA. She said that the EMA coinfection rate was estimated at 18.6% and the Philadelphia rate was 17.5%. She noted that approximately 84% of PLWH in the Ryan White system were screened for HCV in Philadelphia. She stated that there tended to be two types of HIV/HCV co-infected patients: those who were infected for decades and those recently infected with HCV. She stated that all HIV-infected patients should be screened for HCV.

K.C. asked how many people were infected with HCV through sex. A. Shirreffs said that, among younger people, around 10% of people were estimated to have gotten HCV through sex. E.C. asked what other modes there were for HCV transmission. A. Cooper stated that transmission could take place through blood exposure, though the methods of transmission listed on the slide were the most common. A community member asked if HCV was transmitted in semen. A. Shirreffs stated that HCV could be transmitted through semen. She said it was not commonly viewed as a STI, but this was changing.

B.R. asked what forms of hepatitis existed. A. Shirreffs stated that hepatitis A through hepatitis E were currently known to exist. She stated that hepatitis A and B were mostly found among foreign populations in the United States. She stated that these populations were more vulnerable to hepatitis C as well. She noted that Dr. Kwakwa from the Philadelphia Department of Public Health was conducting research about hepatitis C among African immigrants.

E.C. stated that he knew a person who was non-ambulatory. He asked for information about hepatitis C to share with his friend. A. Shirreffs stated that she could provide him with handouts. M.W. asked how long the hepatitis C virus could live outside the body. A. Shirreffs replied that it could live outside the body for several weeks. B.R. stated that hepatitis C tests could be done very quickly. A. Shirreffs explained that there was a rapid hepatitis C test. She noted that there was not a robust HCV testing system like there was for HIV. B.R. asked if Health Center 1 did rapid HCV tests. A. Shirreffs replied that they currently did not. She stated that Philadelphia FIGHT, Bebashi, and Prevention Point had walk-in hepatitis C tests available. G.T. stated that the Washington West Project also offered HCV testing.

K.C. asked if people who had rapid hepatitis C tests could get in treatment after a positive diagnosis. A. Shirreffs explained that a confirmatory test was required before someone could get in care. E.C. asked if HCV was similar to Tuberculosis. A. Shirreffs said it was, in the sense that the virus would not go away without treatment.

A. Shirreffs stated that more research had been devoted to HIV in recent years. She said the federal government had been prioritizing HIV/AIDS research over hepatitis C research. She noted that there were tools to begin the process of ending HIV/AIDS. She noted that, in order to end the epidemic, prevention, testing and diagnosis, linkage to and retention in care, and treatment were all necessary. She stated that the services that supported each goal were multifaceted. E.C. asked if A. Shirreffs had any literature on treatment for HCV. He said he'd like to distribute this information to other members of the community. A. Shirreffs stated that she'd like to help develop promotional materials letting people know that a cure for hepatitis C was available.

B.R. stated that the HCV cure was expensive. E.C. asked if regular insurance paid for it. K.C. noted that people could be re-infected with HCV after treatment. He said that Medicaid and other public programs would only pay for treatment once. A. Shirreffs explained that people who were HCV/HIV co-infected were prioritized in treatment. She said that people who were mono-infected with hepatitis C had more difficulty getting treated than people who were co-infected with HCV and HIV. She noted that the course of treatment for hepatitis C was extremely expensive. She noted that drug companies negotiated with state agencies to reduce the cost of treatment. She said it was unclear what the true cost of the treatment was. She said when the drugs first came out, patients had to prove their sobriety to get treatment and meet certain requirements for impaired liver function. She stated that the sobriety requirement had been removed, and the liver measurements were changed. She added that treatment should be opened up more soon.

B.R. asked if untreated HCV could be fatal. A. Shirreffs said that it could. She noted that fatality rates for HCV varied. She said that HCV could cause severe cirrhosis or liver cancer. E.C. asked why access to HCV treatment would be opened up soon. A. Shirreffs said legal advocacy had helped to open up treatment. She stated that ACT UP had engaged in the same advocacy organizations that she herself participated in. A community member asked if liver cancer rates were increasing. A. Shirreffs stated that they were.

A. Shirreffs displayed an HIV care continuum bar graph. She stated that there was still work to be done in order to get people living with HIV/AIDS virally suppressed. She stated that Philadelphia had the tools to eradicate hepatitis C but needed more resources. She reviewed the factors that were needed to eliminate the hepatitis C epidemic, including prevention, testing and diagnosis, linkage to and retention in care, and treatment.

B.R. stated that he had been told that he could not be re-infected with hepatitis A due to prior treatment for the virus. A. Shirreffs replied that this was true; however, it was possible to be reinfected with hepatitis C. A community member asked if there were vaccines for hepatitis. A. Shirreffs stated that there were vaccines for hepatitis A and B. B.R. asked what the symptoms were for hepatitis C. A. Shirreffs stated that around 20% of people saw symptoms from hepatitis C when they were acutely infected. She said that some people experienced flu-like symptoms. However, she stated that symptoms that showed up later in the infection could indicate liver damage.

A. Shirreffs said that a funding opportunity announcement went out last year asking jurisdictions to apply for a grant to eradicate HCV among people with HIV. A. Shirreffs stated that Philadelphia had received a grant. She said it had been difficult for the health department to collaborate due to AACO and Philadelphia's hepatitis C services being located in 2 separate locations. She said that building off the HIV infrastructure could increase availability of HCV resources.

A. Shirreffs reviewed the goals of the project – to increase Philadelphia's capacity to provide needed HIV services among HIV/HCV co-infected people in Philadelphia, and to increase the number of HIV/HCV co-infected people who are diagnosed, treated, and cured of HCV infection. She said that there were 4 elements to the program, which were data & evaluation, training & capacity building, linkage to care, and service integration. She explained that the data sites for HIV/HCV were at 2 separate facilities. She explained that the program aimed to collect data on HIV/HCV co-infection diagnosis and treatment and provide program monitoring. She said that data for HIV and HCV needed to be combined to see who was co-infected. She said that around 3000 people who were co-infected were lost to care. She said that program staff were asking RW care providers to collect more HCV information by putting new measures in CAREWare. She stated that this data would help evaluate care sites for how well they were doing with diagnosing and treating HCV. B.R. noted that there was mandatory reporting by doctors for people who were infected with an STI. A. Shirreffs answered that hepatitis A, B, and C were all reportable conditions.

E.C. asked what forms of hepatitis were the most damaging. A. Shirreffs stated that hepatitis B and C would be the most dangerous. However, she said there were many more people in the US who had hepatitis C than hepatitis B. A participant asked what type of infections A. Shirreffs was referring to. K.C. noted that coinfection was infection with hepatitis C and HIV.

B.R. asked if hepatitis C could cause intolerance to alcohol. A. Shirreffs stated that it may. She said that it was recommended that people who were diagnosed with HCV cut back or stop drinking alcohol. M.C. asked what sort of barriers existed to HCV treatment. A. Shirreffs stated that there was stigma against HCV because of its association with drug use. She said that some providers did not know how to effectively treat people who used drugs.

B.R. asked if the PDPH was being adequately funded for hepatitis C and STI services. He noted that the rates of syphilis and gonorrhea were going up. He stated that some states and cities were cutting back on free testing. A. Shirreffs said that Philadelphia suffered from a lack of funding, but was better off than some other areas. M.W. said that he went with a group to Harrisburg to advocate for

Medicaid coverage for HCV treatment. A. Shirreffs stated that HCV treatment was currently covered by Medicaid.

K.C. stated that pharmacies may refuse to dispense syringes. A. Shirreffs stated that Prevention Point provided syringe exchange. She said that syringe exchange required local sanction in order to operate in Pennsylvania. She stated that some syringe exchange programs operated underground. She stated that there was some advocacy going on around syringe exchange. A participant asked if HCV could be transmitted by tattoos. A. Shirreffs said it could, particularly at unlicensed tattoo parlors. K.C. stated that tattoos and piercings in prison often resulted in hepatitis C infection.

A. Shirreffs stated that training and capacity building was currently being conducted with area providers around HCV. She reported that some sites were already treating people with HCV, whereas other sites were not doing as well with treatment. She noted that the program was working with the AIDS Education Training Centers (AETCs) to build provider capacity. She stated that, ideally, patients would be treated at organizations where they got their diagnoses rather than being referred out.

A. Shirreffs stated that the grant also covered linkage to care. She stated that this involved supporting people at getting into treatment once they were diagnosed. She explained that, in the long run, medical case managers (MCM) would facilitate linkage to care. She stated that linkage coordinators would also be hired on a health department level.

A. Shirreffs reiterated that the PDPH's hepatitis, STI, and HIV programs were not very well integrated. She said part of this was due to funding limits, but other parts were simply due to the way that the PDPH operated. She stated that one of the goals of the program was to increase this coordination.

A. Shirreffs noted that the jurisdiction was in the process of refining Philadelphia's HCV programming plan. She said that feedback from the community would be beneficial, and focus groups were being held to gather this feedback. She asked anyone who was interested to speak with A. Cooper about potentially participating in the focus groups. She stated that participants would receive food and gift cards. She said a date had not yet been scheduled for the focus groups. Several participants stated that the morning was the best time for focus groups. D.G. noted that there were many meetings at the OHP on Thursdays. A. Shirreffs stated that she'd present to the group again when she knew more about the implementation of the program and more data was available.

Discussion Items:

• Priority Setting Review

A. Boone asked if any attendees had participated in Ryan White priority setting in the past. D.G. explained that the federal government required 75% of Ryan White grant funding be placed in core services with 25% maximum in supportive services. He explained that different factors were used to numerically rank service priorities.

A. Boone explained that the OHP collected information throughout the year to gauge consumer needs. He said that the RWPC had traditionally planned care services for Philadelphia, Southern NJ, and the PA suburbs, though it was now being integrated with the prevention planning body. He stated that many providers participated in the Planning Council on the second Thursday of each month to

talk about services. He asked the group if anyone had heard of PrEP. Several members indicated they had.

A. Boone said that planning for priority setting would be coming up. He said that the Needs Assessment and Comprehensive Planning Committees of the Planning Council were working together on priority setting.

A. Boone said the group would be playing a game modeled on "Who Wants to be a Millionaire." He reviewed many multiple choice questions. He began by discussing the priority setting process. K. Carter noted that there was always a need for transportation and housing services. He asked participants to share any information that they had about their needs. A. Boone reviewed the roles of the Comprehensive Planning Committee, Positive Committee, and Finance Committee. He noted that anyone could come to the priority setting meetings. He added that anyone who was interested could apply for the Planning Council.

E.C. asked if members could be removed from the Planning Council. A. Boone stated that people with attendance issues could be removed from the Planning Council. He explained what was discussed at priority setting meetings. D.G. noted that the OHP and Planning Council did not decide which providers got funding. He explained that epidemiological data about of the EMA, service utilization data, and needs assessment data were all given out at the priority setting meetings to help members make informed decisions.

Old Business: None.

New Business: None.

Announcements: G.T. stated that ACT UP was having a rally next Thursday. She said that she had flyers for the event and invited anyone who was interested to talk to her.

K. Carter said AIDS Education Month was held in June, and registration was beginning for its events.

M.C. reported that it was Autism awareness month and sexual assault awareness month.

Adjournment: The meeting was adjourned by general consensus at 1:53p.m.

Respectfully submitted by,

Jennifer Hayes, Staff

Handouts distributed at the meeting:

- Meeting Agenda
- February 13, 2017 Meeting Minutes
- OHP Calendar