Houston Area HIV Services Ryan White Planning Council Office of Support

1440 Harold Street, Houston, Texas 77006 832 927-7926 telephone; http://rwpchouston.org

Memorandum

To: Members, Affected Community Committee

Johnny Deal, Co-Chair Kathryn Fergus Kakeshia Locks Carol Suazo, Co-Chair Cecilia Ligons Calvin Mills Servando Arellano Tana Pradia LeeAnn Moody Ryan Rose Skeet Boyle Veria Steptoe Tyronika Tates Caleb Brown Diondra English Tony Crawford Ronnie Gallev Revnauld White

Members, Consumer & Community Engagement Education Workgroup

Adonis May
Calvin Vannoy
Pieus Bowser
Cydney Clay
Damion Sam
Rodney Mills
Richon Ohafia
Ocran Holloway
Abraham Arguello
Omar Navarro
Tyvance Credit

Cc: Josh Mica Sha'Terra Johnson

Mauricia Chatman Reachelian Ellison Cydney Clay Richon Ohafia

From: Tori Williams, Director, Ryan White Office of Support

Date: Tuesday, May 13, 2024

Re: Meeting Notice

Please join us for a joint meeting of the Affected Community Committee and the EHE/Integrated Plan Consumer and Community Engagement Education Workgroup. Details are as follows:

Affected Community & Consumer & Community Engagement Meeting 11:00 a.m., Monday, May 20, 2024

Lunch will not be provided but in-person attendees can purchase their own lunch and submit receipt for up to \$10 for reimbursement

Virtually: Click on the following link to join the meeting:

https://us02web.zoom.us/j/81032740414?pwd=V1hTMnltaklDanBDNU9XYkVkdllTZz09

Meeting ID: 810 3274 0414 Passcode: 125162

Or, use your telephone to dial in: 346 248 7799

In-person location: Bering Church 1440 Harold Street, 2nd floor, Houston, Texas 77006

(Please park and use the entrance behind the church facing Hawthorne Street)

Please be sure to contact Rod to tell her if you will be attending in person, virtually or not at all. She can be reached at: Rodriga.Avila@harriscountytx.gov or by telephone at 832 927-7926. We look forward to seeing you next Monday!

Houston Area HIV Services Ryan White Planning Council

Affected Community Committee & the Consumer & Community Engagement Workgroup Meeting 11:00 a.m., Monday, May 20, 2024

In-person meeting location: Bering Church 1440 Harold Street, 2nd floor, Houston, Texas 77006. Please park and use the building entrance behind the church facing Hawthorne Street.

Or, join us via Zoom at:

https://us02web.zoom.us/j/81032740414?pwd=V1hTMnltaklDanBDNU9XYkVkdllTZz09

Meeting ID: 810 3274 0414 Passcode: 125162

Or, use your telephone to dial in: 346 248 7799

AGENDA

I. Call to Order

Johnny Deal and Carol Suazo, Co-Chairs

- A. Welcome and Introductions
- B. Announce who will be chairing the meeting
- C. Moment of Reflection
- D. Adoption of the Agenda
- E. Approval of the Minutes

II. Public Comment

(NOTE: If you wish to speak during the Public Comment portion of the meeting, please sign up on the clipboard at the front of the room. No one is required to give his or her name or HIV status. All meetings are audio taped by the Office of Support for use in creating the meeting minutes. The audiotape and the minutes are public record. If you state your name or HIV status it will be on public record. If you would like your health status known, but do not wish to state your name, you can simply say: "I am a living person with HIV", before stating your opinion. If you represent an organization, please state that you are representing an agency and give the name of the organization. If you work for an organization, but are representing yourself, please state that you are attending as an individual and not as an agency representative. Individuals can also submit written comments to a member of the staff who would be happy to read the comments on behalf of the individual at this point in the meeting.)

III. Old Business

- A. Road 2 Success Updates on hold until sandwich trays can be provided
- B. EHE/Integrated HIV Prevention and Care Plan
 - Merge with College Workgroup? See structural diagram
 - Review March EHE/Integrated Planning Activities Summary, see attached
 - Task for Committee Members create list HIV resources at Houston area colleges

IV. New Business

- A. Project LEAP/Proyecto VIDA 2024 Student Recruitment
- V. Announcements
- VI. Adjourn

Optional: Members meet with committee mentor

Johnny Deal

Houston Area HIV Services Ryan White Planning Council

Affected Community Committee Meeting

12:00 pm, Monday, March 25, 2024

Meeting Location: Zoom teleconference call and at
Bering Church, 1440 Harold St., Houston, Texas 77006

MINUTES

MEMBERS PRESENT	MEMBERS ABSENT	OTHERS PRESENT
Johnny Deal, Co-Chair	Carol Suazo	Reachelian Ellison, TRG
Skeet Boyle	Servando Arellano	Sha'Terra Johnson, TRG
Caleb Brown	Tony Crawford	Mauricia Chatman, RWGA
Kathryn Fergus	LeeAnn Moody, excused	Josh Mica, RWPC Chair
Tony Crawford	Ty Tates	Cidney Clay, COH
Cecilia Ligons		Veria Steptoe
Tana Pradia		
Ryan Rose		OFFICE OF SUPPORT
Diondra English		Tori Williams
Ronnie Galley		Rod Avila
Kesh Locks		
Reynauld White		

Call to Order: Johnny Deal called the meeting to order at 11:06 a.m., and asked for a moment of reflection. Deal invited everyone present to introduce themselves.

Merger with the Consumer & Community Engagement and Education Workgroup quorum and voting recommendations: Williams stated that the Affected Community Committee agreed to merge their meetings with the EHE/ Integrated Plan workgroup. The Consumer and Community Engagement Education Workgroup also agreed. Members of both groups will be considered as Affiliate Committee members with voting rights.

Adoption of the Agenda: <u>Motion #1</u>: it was moved and seconded (Boyle, Galley) to adopt the agenda. **Motion carried unanimously.**

Approval of the Minutes: <u>Motion #2</u>: it was moved and seconded (Boyle, Ligons) to approve the February 19, 2024 minutes. **Motion carried.** Abstentions: Stepteoe and Clay.

Public Comment: None.

Old Business

Medical Need for Food Form: Williams reminded all members to turn in the food form indicating a medical need to take food with medication. The form was been included in the meeting packets. While we are still waiting for the remaining 60% of the FY24 budget, staff cannot provide sandwich trays for those with a medical need. But, those who have turned their form in to Rod and are attending the meeting in person, can pick up their own lunch and be reimbursed up to \$10 by providing a receipt to Rod. See Rod if you have questions, especially the new Committee members.

2024 Greeters: Williams thanked Locks, Tate, and Galley, who signed up to be greeters at all 2024 Council meetings. Greeters need to be in place at least 30 minutes before the meeting starts so they can assist visitors and others. Please see the attached chart of greeters.

Road 2 Success: Williams explained that Road to Success is a program where committee members host HIV educational meetings throughout the community. The 2023/2024 educational goal is to teach consumers how to use the HIV Resource Directory, more commonly known as The Blue Book. The teaching tool is "Blue Book Jeopardy" which encourage participants to answer questions by locating the information in the Blue Book. The first individual to find the information wins a small prize. Galley added that Road to Success has been well attended (at least 90 participants as of 03/28/24), including the meeting with mono-lingual Spanish speaking individuals.

Review EHE/Integrated Planning: Williams provided a brief explanation of the EHE/Integrated Planning and reviewed the goals that were to the workgroup/committee. The group has three years to complete the goals. Members took turns reading each goal out loud. Williams also shared the February 2024 EHE/Integrated Planning Activities Summary Report. (See attached for both documents)

Announcements: none

Adjourn: Motion #3: it was moved and seconded (Boyle, Rose) to adjourn the meeting at 12:02 p.m.

Motion carried unanimously.

Submitted by:

Approved by:

Tori Williams, Director

Date

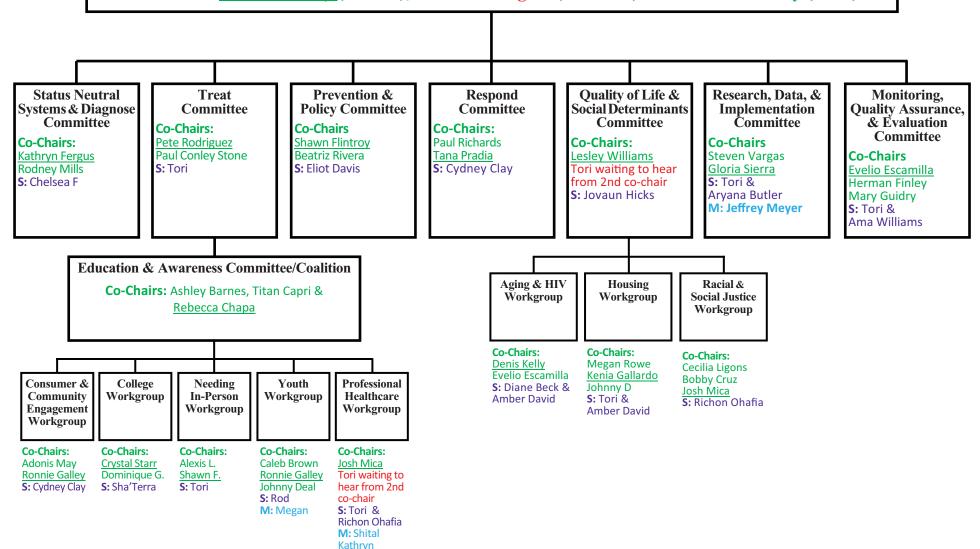
Committee Chair

Date

Leadership Team

REV: 02/29/24

Co-Chairs: Ronnie Galley (RWPC), TRG working on (RW Pt B) and Shawn Flintroy (CPG)



Ending the HIV Epidemic/Integrated HIV Prevention and Care Planning Body

Summary Reports from Committees and Workgroups March 2024

The following EHE/Integrated Planning Body committees and workgroups met in March 2024. Each group discussed their committee/workgroup goals and determined activities for their group over the next couple of months.

Aging & HIV Workgroup, 03/20/2024, Diane Beck, Ryan White Office of Support (RWOoS)

Shital Patel, MD, medical director of the Houston AIDS Education and Training Center (AETC), presented information on the training program currently being developed for Ryan White Part A—funded HIV case managers who will receive training in gerontology. They are surveying and holding focus groups with case managers to determine topics to be included in the training. Her colleague, Vaishnavi Sankar, presented preliminary data from an HIV and aging needs assessment conducted with agency staff. Diane will distribute the presentations to all members. In May, there will be a presentation from Senior Research Associate Daniel Castellanos, DrPH, at the Latino Commission on AIDS. The workgroup would like to receive information about best practices for frailty screening for people living with HIV and how to educate doctors on which tests they should run.

Next Meeting: Noon, Wednesday, May 15, 2024.

Consumer & Community Engagement Workgroup, 03/25/2024, Cydney Clay, Houston Health

Department (HHD). Members discussed *Road 2 Success* classes hosted by members of the Ryan White Affected Community Committee and held at Ryan White–funded agencies, HOPWA-funded housing sites and more. The classes are designed to provide consumers with information about the HIV care system in the Houston 10-county area. The focus of the FY 2023–2024 classes is teaching consumers how to use the Houston Area Directory of HIV Prevention and Care Services, more commonly known as *The Blue Book*. Office of Support staff created a *Blue Book* Jeopardy game that makes the class fun and interactive. Since December 2023, over 103 **non**-Ryan White volunteers have participated in the training. **Next Meeting: 11 a.m., Monday, May 20, 2024.**

Housing Workgroup, 03/28/2024, Tori Williams, RWOoS

In reviewing the goals and seeking to build on existing data, members discussed contacting sources, including the University of Houston School of Social Work, which is believed to hold housing data that students collected and which may be useful in meeting current workgroup goals. City of Houston Director of Housing Opportunities for Persons with AIDS Megan Rowe, a workgroup co-chair, will assist in obtaining Consolidated Annual Performance and Evaluation Reports about housing program accomplishments locally. Other existing HIV-related agencies, housing enterprises serving the aging population (including short-term health recovery options), initiatives monitoring local health issues affecting housing, and others serving housing needs of the community at large were also identified as sources of retrievable information meaningful in meeting goals. **Next Meeting: 2 p.m., Thursday, May 23, 2024.**

Needing In-Person Engagement Workgroup, 03/13/2024, Tori Williams, RWOoS

Members identified a number of individuals who will be recruited to join the workgroup, including people who work in harm reduction, those who work with sex workers, and others. AETC is willing to work with the members to develop HIV training for case managers who work with the homeless. There are approximately 1,000 such case managers in Harris and surrounding counties. And, this summer, Project LEAP students will be asked to work with HPD officers who specialize in mental health to develop a pamphlet listing HIV, mental health and other resources for those living on the street. **Next meeting: 10 a.m., Wednesday, May 8, 2024.**

Prevention and Policy Committee, 03/12/24, Eliot Davis, HHD

Members reviewed goals and discussed identifying an HHD representative to address the committee on HHD

strategy and plans for implementation of EHE-related activities. Advocates/experts supporting and opposing condom distribution to persons who are incarcerated are needed to inform the committee. These tasks were assigned. Members discussed a hybrid model for meeting and endorsed exploring a strategy, such as a resource hub, to minimize duplication of efforts. **Next meeting: Noon, Tuesday, May 14, 2024.**

Racial and Social Justice Workgroup, 03/19/2024, Richon Ohafia, Ryan White Grant Administration Members discussed existing work completed by the University of Houston School of Social Work and morbidity and mortality data for Harris County. They discussed goals for the workgroup and needing a better understanding of the purpose of the group and the meaning of racial/social justice and root causes members are looking to address. Tori is trying to locate a speaker to share tools developed by the Ft. Worth Planning Council, which relate to addressing and supporting racial and social justice issues. Next meeting: 6 p.m., Tuesday, May 21, 2024.

Research, Data, and Implementation Committee and Monitoring, Quality Assurance, and Evaluation Committee, 03/14/2024, Tori Williams, RWOoS Many of those assigned to develop evaluation plans for specific committees and workgroups met with their groups and learned more about their planned activities. Next Meeting: 2 p.m., Thursday, May 9, 2024.

Respond Committee postponed meeting until 1 p.m., Wednesday, May 22, 2024.

Status-Neutral Systems and Diagnose Committee, 03/13/2024, Chelsea Frand, HHD

The committee reviewed its goals and activities and described the current status of each. The team discussed keeping track of activities that take place in the community by using an online tracker accessible to multiple representatives of local organizations and perhaps distribute a survey or host a quarterly call or online forum with them. Such links could help identify specific services, such as those currently offering nontraditional hours. The committee will identify additional members as well as resources that can assist with carrying out the activities assigned to the Status-Neutral Systems and Diagnose Committee. Co-chair Kathryn Fergus will create a survey form that will go to community partners to capture activities conducted by local agencies. Tori will see if other committees/workgroups have survey questions they want to add. **Next meeting: 3 p.m.**, **Wednesday, May 8, 2024.**

Treat Committee, 03/08/2024, Tori Williams, RWOoS

Members of the Treat Committee reviewed Integrated Planning goals more thoroughly, identified community leaders they wish to recruit for membership and identified groups that may be already engaged in efforts that relate to the committee's assigned goals. To meet goals, the co-chairs expressed interest in surveying case managers who work with people living with HIV and those who are homeless to find out what barriers individuals face in securing and maintaining identification documents and how the committee can help them replace documents needed to access care; determine if Harris County Centralized Patient Care Data Management System (CPCDMS) can be used to provide proof of residency, income and other essential data to make it easier for clients to go through eligibility screenings. Other actions included seeking clarification of Goal 2D by sending it back to the SMART Committee that wrote it; creating a list of agencies providing afterhours care; learning more about the Ryan White–funded position of retention nurse at Cambridge Health Alliance (Cambridge, MA), which helps ensure care, treatment adherence and more. **Next Meeting: Noon, Friday, May 10, 2024.**

Youth Workgroup, 03/04/2024, Rod Avila, RWOoS

Members discussed how best to set up a Youth Council. Three organizations that work with homeless youth, or those with a history of homelessness, were identified. Staff and workgroup members will reach out to the three organizations and see if there is an interest in partnering to develop a monthly, in-person (possibly hybrid) educational program for their clients. **Next Meeting: 6 p.m., Tuesday, May 7, 2024.**

Date:	

HIV Services Available at Houston Area Colleges

Your name:	Your email address & phone #:	
Name of College:		
Information collected by:	Telephone Website Other:	
QUESTIONS:		
Where can a student get info	ormation about HIV? On campus Off campus	
Name and phone number of	place or program where educational information is provided:	
Where can a student at the	college get an HIV test? On campus Off campus	
Name and phone number of	place or program where HIV test is administered:	
Is there a charge for the test	? No Yes Cost of the Test: \$	
	college get information about HIV prevention & care services?	
If a student thinks they may	have been exposed to HIV, where can they go for help?	
If there is a place on campu offered?	s where students can get HIV services, what services are	
HIV Testing? PrEP?	P HIV Medicine? Referrals for Services? Counseling?	
Other? Describe:		

TheBody

What's Next For HIV Treatment?

Some State ADAP Programs Are Not Covering Long-Acting Injectable HIV Medications Like Cabenuva

May 10, 2024 By: Tim Murphy



GettyImages/DIGICOMPHOTO/SCIENCE PHOTO LIBRARY

In recent years, long-acting injectables (LAIs) have broadened the HIV treatment landscape. Cabenuva (cabotegravir + rilpivirine), FDA-approved in early 2021, is administered via injection at a health care provider's office monthly or every other month and eliminates the need for daily oral HIV medication. This is a promising option for those living with HIV who, for various reasons, can't or won't use daily pills. Additionally, Trogarzo (approved in 2018) and Sunlenca (approved in 2022) are powerful injectable options to add to oral regimens specifically for those living with HIV who have developed resistance to other medications.

However, a number of AIDS Drug Assistance Programs (ADAPs) across the U.S. do not cover those injectables. According to leadership at the International Association of Providers of AIDS Care (IAPAC) and Fast-Track Cities (a global effort to bring the epidemic to an end, of which IAPAC is a key partner), this is a problem in six states—Missouri, Kentucky, Louisiana, Oklahoma, Texas, and South Dakota—as well as some U.S. territories, such as Guam and American Samoa.

ADAP is a federal/state program covering medications and care for people living with HIV who are uninsured or underinsured; what the program offers, and to whom, varies by state. Some officials, including José Zuniga, Ph.D., M.P.H., IAPAC's president, told TheBody that denying "folks the choice [to take injectable medications] is wrong, particularly for people who are really challenged in taking daily pills." During a phone interview, he said that states, whose ADAP offices decide what drugs should be covered, should not use the high cost of the injectables as a reason not to cover them.

Cabenuva, for example, <u>costs</u> about \$40,000 annually. Meanwhile, cash payment for the daily oral HIV regimen Biktarvy is even higher, almost \$4,000 a month. Zuniga said that in the majority of states whose ADAPs do cover injectables, fewer than 10% of all people living with HIV in the ADAP program are using them.

Keep in mind that these list prices do not tell the full story. For instance, it is well known that ADAP is empowered to negotiate a more favorable rate on drug prices and, therefore, the final overall cost might be less. For insight into the actual cost of these medications, TheBody reached out to Tim Horn, M.S., director of NASTAD's Public Health Systems team. Through email correspondence, Horn explained:

"Generally speaking, the ADAP Crisis Task Force is able to secure discounts and rebates on antiretroviral drug products that are more than 50% below their list prices. So, while many ADAPs may have a gross expenditure of approximately \$43,000 annually for every client using Cabenuva, their net expenditure—following the collection of rebates down to a sub-340B price negotiated by the ADAP Task Force—is substantially less. The same is true [regarding ADAP's negotiation on the annual cost] of Biktarvy."

Zuniga claimed that officials in the Texas ADAP program recently said that they would have to shell out \$6.4 million a year to provide Cabenuva alone. But Zuniga said that figure reflects if *all* Texas ADAP recipients in the state switched to Cabenuva, which he said was highly unlikely to happen. In an <u>article</u> last year, the CEO of ViiV, which makes Cabenuva, said that, in its current form, which needs to be received at a health care provider's office, the drug likely would not exceed 15% of market share among HIV drugs.

Whether ViiV's estimate is correct or not, what fiscally conservative health administrators are missing is that even if a majority of Texas' ADAP recipients switched to Cabenuva, if that change led to increased viral suppression and optimal health outcomes, it is likely that the overall savings in reduced care would dwarf the financial cost.

ADAP Responses Diverge Widely by State

Between mid-April and early May, TheBody reached out multiple times by email and phone to ADAP offices in the seven states that IAPAC had originally said were not covering injectables. TheBody asked the offices to confirm IAPAC's claim—and, if it was true, why they were not covering injectables and if they were discussing or planning to do so currently or in the future.

Three state ADAPs ultimately replied with full answers, rather than promising information and not following up.

In Missouri, Dustin Hampton, M.Ed., a bureau chief of the state's health department—within which ADAP is administered—called to say that the state's ADAP covers <u>Sunlenca</u> but would only cover Cabenuva via a special approval process involving a pharmacy benefits manager. These managers function as gatekeepers between insurers and pharmacies, meant to keep costs down. Asked how many people with HIV in the state were currently on Cabenuva via that process, Hampton said he would get back with that number, but he didn't.

A representative from Texas ADAP replied via email to say that the program is covering <u>Sunlenca</u> and that "the feasibility of the addition of Cabenuva to [Texas ADAP's] formulary is currently under review" by the state health department. The representative confirmed that recipients of Texas' ADAP *had* requested Cabenuva and that, until it comes onto the program's formulary, there are "local options" including "local funding" that might cover the drug for those who need it.

A representative from Louisiana ADAP replied via email to say that the program in fact covers LAIs for recipients who are using the program to pay for full insurance, "as long as the medication is on their insurer's plan formulary," and that, in fact, 94% of program recipients have full insurance. Of those who do not and rely on the direct ADAP formulary, the representative said, the majority of them are in a jurisdiction where the ADAP formulary indeed *does* cover LAIs. For those not in that jurisdiction, the representative said, the program released a request for proposals (RFP) early this year to procure services that would lead to LAIs being covered.

Zuniga urges everyone in the HIV community to do what they can to push these outlier ADAPs to cover not some but all currently available LAIs. "Community activism to demand access to treatment options is a hallmark of the U.S. HIV response," he said. "We urge people living with HIV who are denied access to LAIs to not give up on access, but work with their clinicians to advocate that state ADAPs prioritize patient choice and facilitate their HIV treatment preferences to achieve #U=U."

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Tim Murphy, Contributing Editor: Tim Murphy, based in Brooklyn, has been writing about HIV/AIDS for 25 years, for publications and organizations including TheBody, TheBodyPro, POZ, New York Magazine, The Nation, Housing Works, and Lambda Legal.

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