



## *SUMMARY*

HIV Medication Access Workgroup Mtg #1  
August 23, 9:30am to 2:00pm via Zoom

**PURPOSE OF THE MEETING:** Orient everyone to the work ahead; learn about and share information on people and issues; review and confirm schedules, norms for working together and expected products.

### **WELCOME, CHARGE AND INTRODUCTIONS**

Manny Santiago, the Executive Director of the Washington State LGBTQ Commission (Commission) welcomed participants to the meeting with the following remarks, and reviewed the charge given to the Workgroup from the Washington State Legislature (Legislature):

*"I have learned throughout my life that complex problems require complex solutions, and there is no magic wand that can offer us that. On the contrary, we must engage, in good faith, in at times long, at times convoluted, and at times even frustrating conversations and actions to find solutions that are sustainable. The Washington Legislature trusted this group of stakeholders, and the LGBTQ Commission, to engage in some of these conversations in the hopes we can find possible solutions.*

*Through a budget proviso, the Legislature has charged the Commission with convening this workgroup, listening to concerns, doubts, ideas, and possible solutions, and finally present a brief report with our suggestions. The charge is found in Engrossed Substitute Senate Bill 5090, sections 118.a-b, and 211.48.a-c. The three main goals of this workgroup are as follows:*

*to consider and develop recommendations regarding:*

- i. Access to HIV antiretroviral drugs on the medicaid drug formulary, including short- and long-term fiscal implications of eliminating current prior authorization and fail-first requirements;*
- ii. Impact of drug access on public health and the statewide goal of reducing HIV transmissions; and*
- iii. Maximizing pharmaceutical drug rebates for HIV antiretroviral drugs.*

*These past few months I've had the chance to speak with many of you or with groups that represent your interests. After these conversations, I can confidently say that everyone here wants the best for the community, and in particular, for those among our*

*community who are living with HIV in Washington and who access medical care through Medicaid.*

*As we enter this work, I want to extend an invitation to all of us to come with an open mind, to recognize that this is hard work, to respect each other's experiences and ideas, as well as the way in which we share these experiences and ideas, and to keep in mind that we all have the best interest of Washingtonians at heart."*

Omar Santana, Program Manager for the Commission, reviewed protocols and norms for the meeting. Manny introduced Martha Bean and Dr. Renee McCoy who will assist in facilitating the group.

Participants in the meeting were invited to introduce themselves, provide their affiliation and describe both how they viewed success for the project ahead, and how they personally could contribute to that success. Throughout the meeting, as other participants logged on, they were invited to introduce themselves.

A list of participants can be found on the final page of this summary.

## **ORIENTATION / LEARNINGS FROM LISTENING**

Martha Bean and Manny Santiago provided information to orient the group to the work ahead. This included a review of the agenda for the meeting, a set of operating guides, and a suggested blueprint for how the Workgroup could choose to organize and compile its report to the Commission.

Manny shared the following observations based on listening he had the opportunity to do as the Workgroup was being formed. Manny offered that it appears there are **key values and perspectives shared by all:**

1. Access to HIV medications for people living with HIV and who participate of Medicaid is very important and should be made as easy as possible.
2. The decision about what type of medication a patient uses should be made by the physician-patient team, not by the government or pharmaceuticals.
3. There should be easy processes to access HIV medication through Medicaid.
4. The patients' health is the priority.
5. The different stakeholders were part of several meetings and processes to develop the current HIV drug formulary.
6. At some point, towards the end of working on developing the current drug formularies for these HIV medications, the parties didn't quite get to the same conclusions on what was most important.
7. Trust has been affected (in all directions.)

Manny also offered observations of where people ***do not share the same understanding*** of the facts and issues. His observations are:

1. There is confusion on how the current formulary works and who benefits from the current processes.
2. The prior authorization requirements feel like the voices of people living with HIV have not been heard.
3. There are questions about the role of pharmaceuticals in these conversations.
4. The voices of people of color living with HIV have not been always present, and sometimes they have been suppressed.
5. There are still other vulnerable communities whose needs have not been always present at the table during the conversations: rural, sex workers, people with disabilities, the elderly, transgender community, immigrants, etc.
6. Information has not always been presented to stakeholders or has been presented in a way that has not felt transparent.
7. The challenges of balancing fiscal responsibility and universal accessibility has not always been understood.
8. The challenges of balancing fiscal responsibility and universal accessibility has been presented in a way that seems to pit one community against another to fight for limited resources.

Discussion among participants followed.

### **TOPICS TO ADDRESS WITHIN THE THREE CHARGES**

The Workgroup was invited to discuss and brainstorm how to meet the charge given them by the Legislature. Three breakout rooms were set up, one for each of the charges. With three rotations of the breakout rooms, each participant had the opportunity to discuss with others the answers to these questions:

- What topics and issues do you want the Workgroup to discuss and consider relative to ACCESS?
- What challenges are associated with ACCESS?
- What information is needed to adequately discuss issues of ACCESS, and where can we get that information in a timely fashion?

The following list attempts to capture key points made during the breakout room discussions, and the reporting out that occurred to the whole Workgroup:

### **Discussion on Charge regarding Access** (facilitated by Renee McCoy, PhD)

- i. *Access to HIV antiretroviral drugs on the medicaid drug formulary, including short- and long-term fiscal implications of eliminating current prior authorization and fail-first requirements.*

The discussion focused on topics, issues and challenges impacting access to medication for persons living with HIV who are also receiving Medicaid. Although participants represented government agencies, pharmaceutical companies, care providers, and persons living with HIV, there was resounding agreement that access was problematic and there needed to be adjustments at the systemic level. To accomplish this, participants offered the following:

- The HCA processes for accessing other drugs should be explored because they might inform access to HIV medications. Access issues regarding other medications for persons on Medicaid might mean access issues for HOV medications occur within the context of deeper systemic problems.
- The Workgroup should consider inconsistencies in access for various groups according to race or geography (i.e., rural vs. urban).
- Processes are not clear. How do access processes differ from those used by persons who are not receiving Medicaid?
- There are challenges navigating the authorization processes. Is there a way to expedite authorization for persons living with HIV?
- There are communication challenges. How is information disseminated to persons living with HIV? How are persons with HIV who are receiving Medicaid involved in establishing and implementing access processes?
- What is the meaning of “access” and how do we measure it?
- What other issues in the lives of persons living with HIV create barriers to access such as transportation, level of mobility, mental health concerns, etc.?
- Providers need additional training regarding access.

**Discussion on Charge regarding Impact** (facilitated by Manny Santiago)

- ii. Impact of drug access on public health and the statewide goal of reducing HIV transmissions
  - Do HIV patients know there’s a pre-authorization process?
  - Clarifications are needed for processes
  - What is the impact on HCA’s budget? We have heard some numbers, but we do not believe those numbers.
  - Challenges of stigma associated with HIV.
  - People are afraid to talk to their physicians about accessing medication and about the process for pre-authorization.
  - What does the literature say about single versus multiple tablet dosages in treatment regimens?
  - What is the impact of different medication regimens?

- Impact to adherence: who will be accessing medication through the different options?
- Impact on adherence: vulnerable and difficult to reach communities.
- What impact do federal guidelines have on local/state protocols?
- Impact of Washington's approach (pre-authorization) on accessing treatment.
- What are the short- and long-term impacts of the different approaches?
- What are the techniques used to reach out to vulnerable communities? Are those having an impact on access to treatment?
- Need to better understand the stories of challenges to access.
- Impact of not having a holistic approach, and person-centered approach to treatment.
- Need for information on impact of the current policies:
- How many requests?
- How many denials and why?
- Health barriers: what's the impact on people whose healthcare providers are not following protocols?
- Is there going to be a slope?
- How will current guidelines impact national guidelines for medication costs and accessibility?
- Concerns with access to quality medication.
- Are the current protocols beneficial for treatment?
- Consequences for people currently not adhering to treatment.
- What are some challenges that people face that affect accessibility?
- What is the impact of the different protocols on pharmaceuticals' approach to advertising directly to the consumer?

#### **Discussion on Charge regarding Rebates** (facilitated by Martha Bean)

##### iii. Maximizing pharmaceutical drug rebates for HIV antiretroviral drugs

The bulk of the discussion regarding rebates had to do with the complexity of the system.

Key points made include:

- Understanding how the rebate system works is a necessary first step for the Workgroup to be able to explore and make recommendations on how to maximize drug rebates.
- Federal and state systems for rebates vary; consequently, DOH and HCA also have different processes in place regarding rebates. The Workgroup wishes to know how and why.
- Some of program requirements for processing rebates may be due to the fact that the price paid by each agency for ARV drugs is based on negotiated contracts that are unique to each agency. The Workgroup wishes to know more about this, and how confidentiality requirements and contract law play into the lack of transparency on cost and, subsequently, on rebates.

- The program and systems used to grant supplemental rebates is also opaque. There is a need to understand the workings of the supplemental rebate program.
- Not all providers and manufacturers participate in rebate programs. Why and why not?
- Some participants would also like to understand how rebates figure into overall cost calculations and value assessments. Other are interested in knowing the challenges to disclosing who gets what rebates and under what conditions.
- The complexity and variability of rebate programs creates a ‘pinch point’ that contributes to a lack of trust among some participants.

## CLOSING DISCUSSION AND COMMENTS

Manny provided additional information and solicited input on Town Halls that are scheduled for September 7<sup>th</sup> and October 25<sup>th</sup>.

Workgroup members were told when the leadership and facilitation team hoped to provide them with materials from this meeting and were also invited to freely give feedback about the meeting to Manny, Omar, Martha, or Renee.

Workgroup members were told to expect they may be asked to help provide information to the group to aid in future discussion, and that they would be asked to review and comment on the report as it is built based on each subsequent Workgroup meeting.

Manny heartily thanked people for their participation, noting that ending HIV/AIDs is the goal of all.

## PARTICIPANTS\* DURING SOME OR ALL OF THE MEETING

*\*This list may be incomplete. Please provide any corrections to Omar Santana*

<b>First</b>	<b>Last</b>	<b>Organization/Profession</b>	<b>Group/Affiliation</b>
Matt	Golden	Medical provider	Healthcare provider
Scott	Bertani	Health HIV	HIV Service Organization
Lauren	Fanning		HIV Service Organization
Jonathan	Frochtz wajg	Cascade AIDS Project	HIV Service Organization
Steven	Sawyer	POCAAN	HIV Service Organization
Melanie	Smith	Cascade AIDS Project	HIV Service Organization
Omar	Santana	PM, LGBTQ Commission	LGBTQ Commission
Manny	Santiago	ED, LGBTQ Commission	LGBTQ Commission
Everett	Maroon	Blue Mountain Heart2Heart	LGBTQ Commission + HIV Service Organization
Dale	Briese	SAN	Peer Navigators
Mark	Garrett		PLWH

Carey	Morris	Equal Rights Washington (ERW)	HIV Service Organization
Erick	Seelbach	PCAF	HIV Service Organization
Devon	Connor-Green	Gilead (lobbyist)	Pharmaceutical Company
Kristina	Hermach	Gilead (lobbyist)	Pharmaceutical Company
Kristen	Tjaden	Pharma	Pharmaceutical Company
Dennis	Torres	Gilead (Community engagement)	Pharmaceutical Company
Mary	Clogston	House Dems Policy Advisor	WA Legislature
Nicole	Macri	State Rep District #43	WA Legislature
Carri	Comer	DOH	WA State Department of Health
Elizabeth	Crutsinger-Perry	DOH	WA State Department of Health
Sue	Birch	HCA	WA State Health Care Authority (Apple Health)
Michelle	Clearly	HCA	WA State Health Care Authority (Apple Health)
Amy	Irwin	HCA	WA State Health Care Authority (Apple Health)
Josh	Morse	HCA	WA State Health Care Authority (Apple Health)
Donna	Sullivan	HCA	WA State Health Care Authority (Apple Health)
Martha	Bean	Consultant to the Workgroup	
Renee	McCoy	Consultant to the Workgroup	

*\*This list may be incomplete. Please provide any corrections to Omar Santana at [omar.santana@lgbtq.wa.gov](mailto:omar.santana@lgbtq.wa.gov)*