



SUMMARY

HIV Medication Access Workgroup Mtg #2
September 13, 9:30am to 12:00pm via Zoom

All materials and presentations for this meeting are available at this link:
<https://lgbtq.wa.gov/advocacy/community-work/hiv-medication-access-workgroup>

PURPOSE OF THE MEETING: Learn about and discuss information requested during August 23 meeting; make progress both identifying and adding context and content to topics to be addressed in report; review and understand seeking agreement, voting and participation.

WELCOME

Manny Santiago, the Executive Director of the Commission welcomed participants to the meeting with the observations based on the results of the August 23rd meeting, and conversations with some Workgroup members prior to September 13. These observations have been added to the document titled "Fact, Issues and Conundrums", initially posted prior to the August 23rd meeting and available at the link above:

- 1. Access to quality care for people living with HIV is still the main concern of all stakeholders.*
- 2. Not everyone is in agreement on what constitutes "quality care" or how it should be measured.*
- 3. The lack of participation from people living with HIV as well as from healthcare providers is still a concern for all stakeholders.*
- 4. Most participants have expressed or shown discomfort or concerns with the pace of the process (too slow or too quick, depending on their lens.)*
- 5. Passion can at times be misinterpreted as personal attacks or as questioning the integrity or the professional ethics of participants.*
- 6. Envisioning creative solutions focused on the future and addressing concerns of all partners continues to be challenging.*
- 7. Participants are building on past experiences and interpretations of work; it is perhaps time to move past this and co-create new realities.*

Omar Santana, Program Manager for the Commission, reviewed protocols and norms for the meeting. Martha Bean, Facilitator for the Workgroup, reviewed the agenda.

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

PRESENTATIONS AND DISCUSSION ON INFORMATION REQUESTED ON AUGUST 23

1- *What can we do to actually understand costs?*

Donna Sullivan/Washington State HCA offered a presentation on relative cost of medications within Washington State and across other states where the information is available. The slides from this presentation can be found at the link at the top of this summary.

In response to the presentation on costs, several Workgroup participants suggested ideas on how to track cost data at a finer grain that could better inform the questions asked by the legislature. Suggestions included:

- a. Track data on the pricing for combinations of treatment and single or multiple pills regimen.
- b. Desegregate data on the single tablet regimen; desegregate and compare price data based on the components of the multi-pill regimen.
- c. A request for more information about and transparency regarding the process for how the HCA transitions to and from multiple and single tablet regimens for patients who require care.
- d. A request to know when the patents for medications are due to expire. This can allow Workgroup participants, and the HCA, to better understand when budgets can change because a drug becomes generic.

Several Workgroup members requested that the HCA to consider reviewing and revising the calculations that lead to the statement by the HCA to the State legislature that moving from a pre-authorization system to 'open access' would cost the state between \$40 and \$60 million per year. In particular, these suggestions were made:

- a. The assumption that 70% of patients may choose to switch from a multi-pill to a single-pill regimen may be high. In particular, this may be high from PrEP medications.
- b. It may be useful for the HCA to calculate the total cost of treatment for a patient. For instance, what is the cost to the State if a patient is unable, for whatever reason, to adhere to the medication regimen prescribed through the HCA? If this is already being done, the Workgroup would like to see and understand this total-cost analysis.

Others felt that a focus on cost obscures inequities in the delivery of care. In particular, while Washington State may have relatively good track record of supporting and treating those with HIV, the question must be asked who is not getting care and why not? Systemic inequities are compounded if those who are not getting adequate treatment are considered 'outliers'. A key question is whether the pre-authorization ('fail first') system, even with new

expedited process options, creates obstacles for underserved and marginalized populations? Several Workgroup members felt that attainable qualitative data is the only way to get at this question, not cost of medications. (See item #3 below in this summary for more discussion on this topic.)

Appreciation was expressed for the compilation of information provided by HCA, and for the willingness of HCA staff to have Workgroup members ask detailed questions about the data, and to ask for clarifications and suggestions about assumptions inherent in the spread sheets.

2- A primer on rebates

Chris Andrews from Artia Solutions provided slides on how the rebate process works. These slides can be found at the link at the top of this summary. It was noted that 42 US Code – 1396.r.8 (b) (3) (D) (https://www.ssa.gov/OP_Home/ssact/title19/1927.htm) regulates the confidentiality requirements for negotiating drug prices and rebates related to HIV medication. Several Workgroup participants find the confidentiality requirements frustrating. Others offered that while frustrating, confidentiality requirements are made at the federal level, and this Workgroup has little power to affect these. In response to this ‘reality check’, some suggested the report from the Workgroup should none-the-less include a clear and direct statement that confidentiality requirements are an impediment to truly understanding actual costs and how to manage them. Still others suggested there may be other ways to understand costs without violating confidentiality agreements. A Workgroup participant asked: Can state agencies request specific cost information that may be considered confidential? The answer was yes, with this caveat: The request must be for specific purposes of policy making and/or legislating, for a specific reason, and the cost information must remain confidential. Additional questions and comments included:

- a. What confidential information can agencies and legislators can request, for what purposes and under what circumstances?
- b. Can signed contracts, with cost information redacted or withdrawn, be made available? This would offer insight into the parameters around how prices are negotiated and set.

3- Experiences in other State:

At the August 23 meeting, some Workgroup participants requested information on how others states work with the challenges posed by access to ARV drugs. The thinking was that other states may have met similar challenges and thus may provide ideas and examples for Washington.

Donna Sullivan/Washington State HCA and Scott Bertani/HealthHIV both presented information on how other State manage HIV medications, primarily focused on whether or not a state has pre-authorization programs in place, and the cost of these programs. Both

presentations also attempted to compare health outcome results, though it was noted this is very hard to do; often an 'apples-to-oranges' comparison.

The presentations, spread sheets and raw data offered by Donna and Scott can be found at the link at the beginning of this summary.

Questions, comments and suggestions included the following:

- a. Washington generally has better health outcomes when compared to other states.
- b. Even so, while Washington's numbers generally look good, several Workgroup members asked all to consider the demographics of those who are not receiving care that works for them. Who are the real people who are left behind? What is keeping these real people from being adequately served? As such, comparing the Washington State process with those of other states may be less enlightening than centering on the experiences of patients in our own state.
- c. It is not necessary to compare our state's process to others; centering the experiences of patients in WA should be the priority.
- d. There is federal (NIH and/or CDC and/or WHO) guidance that calls for open access to [all ARV or is it just PrEP?] <https://www.npr.org/2021/07/29/1022255279/feds-are-making-hiv-prevention-treatment-free> and <https://www.dol.gov/sites/dolgov/files/EBSA/about-ebsa/our-activities/resource-center/faqs/aca-part-47.pdf>; it may be buried here <https://clinicalinfo.hiv.gov/en/guidelines/adult-and-adolescent-arv/cost-considerations-and-antiretroviral-therapy> (see very useful table 22a; also and 22b)

4- ***The meaning and measurement of both efficacy and access:***

While there was no presentation on the meaning and measurement of both efficacy and access, much of the discussion of the information presented thus far included comments on this topic. In particular, some Workgroup participants advocated for measurement of health outcomes for people living with HIV in Washington state, taking into account issues such as mental health, comorbidities and illnesses, disabilities, English proficiency, systemic racism, homelessness, ability to adhere to a treatment regimen, lack of access to transportation, inflexibility of work hours, the working poor and stigma.

Participants raised concerns about leaving the stories of people living the HIV from the conversation on processes and establishing guidelines for access to medications. There were also concerns of not centering the lives and needs of PLWH when making decisions on processes to access medications. There are also repercussions on adherence when the stories of people who experienced challenges accessing medications through the current system are not heard or addressed. Some expressed deep concern about the impact to the

mental health of patients when processes and information are not transparent; this can add to trauma already experienced by those affected by HIV/AIDs.

As has been noted on several other occasions, the Workgroup is not complete without representation from people living with HIV, and without the voice of care providers. While community organizations can do some outreach to people living with HIV, they are limited. Health care providers frequently have little time to participate in a workgroup setting such as this one. The Town Halls scheduled for September 20 and October may help to expand the number and breadth of perspectives included. Surveys could also be employed.

BRAINSTORM ON WHAT TO INCLUDE IN REPORT

Workgroup participants were invited to provide ideas on what can go into the report from the Workgroup. Ideas included:

- a. Get more detailed data on how the pre-authorization program works for actual patients and their providers in real-life settings. Include a review of viral suppression and transmission in this review. Qualitative data can be gleaned from any number of sources, while maintaining patient confidentiality
 - Interview Title XIX care coordinators; providers on their experiences
 - Review medical records with names redacted; progress notes, chart notes may be helpful. It is challenging, but not impossible, to do this within health confidentiality requirements.
- b. As this qualitative data is gathered, assure data is collected on the numerous things Workgroup members have identified that impacts the overall efficacy of treatment. For instance: access to transportation; other diseases or conditions, effects of poverty (see elsewhere in this summary for additional topics).
- c. Help the legislature see “ancillary” and life-cycle costs. If the legislature is only presented with the costs of drugs, this is not the full picture.
 - Other information (e.g., viral suppression rates) are brought to the legislature and are part of state analyses on efficacy of the program, but there may be other places to get information to get the full view of the costs of having a segment of the population that does not get treatment that works for them.
 - HIV infection rates are going up. This reality means HIV isn’t completely analogous to other chronic diseases. Consequently, the legislature should see short, mid- and long-term costs.
- d. Understand that the goals of EndAIDS2020 cannot be met as long as there is even one individual who is not receiving the treatment and care that works for them. It is important to fully understand who these people are, and how to get them treatment. Part of this is about ease of access to drugs.
- e. How we treat and speak with one another, and the assumptions made about intentions, are a barrier.
- f. Explore ways to simplify and expedite the pre-authorization process. Consider that perhaps it is not the lack of open-access per se that is the problem, but the

ability of patients and providers to effectively and efficiently use the pre-authorization system.

- g. Understand if the challenges associated with pre-authorization are due to which drugs are on the pre-authorization list, or if the challenges are associated about the process to get pre-authorization, especially for those with complicated lives.

PARTICIPANTS* DURING SOME OR ALL OF THE MEETING

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

First	Last	Organization/Profession	Group/Affiliation
Scott	Bertani	Health HIV	HIV Service Organization
Jonathan	Frochtzwajg	Cascade AIDS Project	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
Carey	Morris	Equal Rights Washington (ERW)	People Living with AIDS/ HIV
Erick	Seelbach	PCAF	People Living with AIDS/ HIV
Devon	Connor-Green	Gilead (lobbyist)	Pharmaceutical Company
Kristina	Hermach	Gilead	Pharmaceutical Company
Kristen	Tjaden		Pharmaceutical Company
Carri	Comer	DOH	WA State Department of Health
Elizabeth	Crutsinger-Perry	DOH	WA State Department of Health
Donna	Sullivan	HCA	WA State Health Care Authority (Apple Health)
Martha	Bean	Consultant to the Workgroup	
Renee	McCoy	Consultant to the Workgroup	
Chris	Andrews	Artia Solutions; guest of Gilead and Workgroup	

Renee	McCoy	Consultant to the	
Chris	Andrews	Presenter on rebates	Guest of Gilead

DRAFT