



**HIV Medication Access Workgroup
Public Town Hall Conversation: Summary
October 12, 2021**

Purpose of this Meeting: This Public Town Hall Conversation was designed to inform the report of the Washington State LGBTQ Commission to the Washington State Legislature concerning access to HIV medications for persons receiving Medicaid benefits in Washington State. It occurred in response to a series of meetings of the HIV Medication Access Workgroup exploring contributing factors and examining strategies to increase access, reduce the spread and burden of HIV, and enhance the quality of life for all persons living with this disease. Significant issues emerged during Workgroup meetings as obstacles to access and a number of options were identified and addressed during this meeting.

SUMMARY OF CONVERSATION

This Public Town Hall Conversation was facilitated by Manny Santiago, Executive Director of the Washington State LGBTQ Commission with assistance from consultants engaged to support this process. Issues identified by the Workgroup were addressed within the framework of

- a) An exploration of the implications of shifting to an “open access” system through independent qualitative research focused on challenges to adherence such as cultural differences other social determinants of health;
- b) The utility of employing investigative methods to better understand the impact of the “fail-first” system on the individual, health care providers, and public health; and
- c) Identifying groups of persons living with HIV who are not being adequately served as well as ways of increasing access to medication and making care more inclusive.

Participants in the conversation included representatives from the HIV community, service providers, care providers, and the public health sector. The conversation unfolded through responses to the following questions:

1. How does the lack of an open access system impact the lives and health of persons living with HIV? How does it affect care providers?
2. How does the fail-first system and petition process impact the quality of life for persons living with HIV? How does this affect the relationship between patients and health care providers? What is the impact of this process on providers?
3. Which groups of persons living with HIV are not receiving the level of access to medications necessary for them to sustain a healthy quality of life? What challenges do they face? What needs to happen for those challenges to be remedied?



I. Open Access

In an effort to operate with shared meanings, the terms “open access” and “fail-first” were defined prior to introducing related questions. “Open access” was defined as processes and procedures for receiving medications that are consistent for all persons living with HIV regardless of whether drugs are funded through private or governmental sources. Currently, this system is not in place and persons receiving Medicaid are required to complete prior-authorization processes to receive certain ARV medications. Participants reported the following:

- It is important to recognize the connection between open-access and fail-first. Both serve to restrict access to medication. Both are the result of the HCA making rules about access and both result in differential treatment, making obtaining treatment and improving the quality of care for persons living with HIV unequal processes that can be burdensome for persons relying on Medicaid.
- Prior authorization is a slow and cumbersome process. It was pointed out, however, that in some situations, pharmaceutical companies have provided medications to persons while they wait for authorization. Although this does not constitute “open-access”, it does decrease the time during which patients are without needed medications.
- Having to employ prior authorization processes causes patients to become fearful about their health. This can be off putting for persons living with HIV.
- The absence of an open-access system reduces the level of trust persons living with HIV have in their care providers.
- The absence of an open-access system and the requirement to receive prior authorization presents serious obstacles to care for persons living with HIV who also receive Medicaid. Also, newly diagnosed persons are less willing to engage in medication regimens.

II. Impact of Fail-First

It was stated that “fail-first” refers to the existing system through which patients must first be prescribed drugs on the prior-authorization list and can only receive different medications after previously prescribed drugs have proven to be ineffective. The only option to access different drugs requires patients and providers to complete a process of petitioning the public health system. During the conversation the impact of this system on relationships with providers and on quality of life and health were discussed.

- Due to the fail-first system, medications are not available when they are most needed.
- Trust relationships between patients and care providers, including physicians and case managers, becomes fractured.



- Patient education is a serious problem, especially for persons for whom English is not their primary language. This leads to inconsistencies in what providers need to communicate and what patients actually understand.
- The fail-first system was described as “unacceptable”, “criminal”, and a system that punishes people for being poor.
- Participants discussed how policies of insurance providers are different. Some providers pay for medications that others do not. This can be confusing and contributes to resistance to care and treatment.

III. Identifying Who Is Missing and Challenges

Although participants did not list specific groups in response to the question of who is missing and how to resolve this challenge, a number of groups and challenges were identified during the course of the conversation.

- **Undocumented Persons:** individuals who are undocumented cannot pay for medications and do not qualify for Medicaid. They are also challenged by language. Access to medications becomes complicated at best or all together impossible.
- **Homeless and Unstably Housed Persons:** individuals who do not have stable housing experience compliance as challenging. For example, they have nowhere to store medications and/or do not have access to nutrition required by some drugs regimens.
- **Transportation:** it is extremely difficult for persons who do not have access to transportation to clinics that have been assigned by specific insurance plans.
- **Transgender Persons:** health concerns of transgender persons are often complicated, involving more than just ARV medications. They face the challenges of identifying providers who are knowledgeable of the complexities of care they face in addition to living with HIV.
- **Persons Dealing with Mental Health Issues:** As with the previous groups, participants discussed the challenge of living with HIV for persons who also have mental health issues. Their abilities to remain compliant to medication regimens are complicated.

IV. Recommendations and Concluding Remarks

Participants agreed that accessing medication will continue to be challenging for persons living with HIV who are also receiving Medicaid. It was suggested that the only solution is to deconstruct the system in order to identify, understand, and address barriers to care. The central and most salient problem is that the present system does not consider the real-life issues they face. It was also stated that the HCA maintains too much control over care and is concerned more with cost saving than care. Some agreed with this sentiment. Additionally, it was recommended that



- Efforts should be taken to make access easier. The existing policies and procedures are far more complicated than necessary.
- Patient education should be improved and expanded so that individuals are better able to advocate for themselves.
- Cultural sensitivity needs to be improved and increased so that providers can better understand the issues and more effectively advocate for their patients.
- Capitalism is central to access difficulties. Both the HCA and the pharmaceutical companies place profit over people. The pharmaceutical companies are concerned with making a profit, while public health is concerned about saving money.

The bottom line of the conversation was that there is resistance to recognizing that access is about real people with real lives. The most salient problem is that real-life issues such as securing childcare, unstable housing, transportation, mental health, and health issues that are ancillary to HIV (i.e., diabetes, cancer, etc.), make accessing and managing HIV medication cumbersome or impossible for poor persons living with HIV.