
The Washington State HIV Response Plan:

2022 Community Engagement Report

February 2023

Brian Minalga, MSW
Contractor for the WA State Department of Health
Contract #PRV27385

The Washington State HIV Response Plan Community Engagement
Report

DOH 150-225 (JULY 2023 ENGLISH)

To request this document in another format, call 1-800-525-0127. Deaf or
hard of hearing customers, please call 711 (Washington Relay) or email
civil.rights@doh.wa.gov.





TABLE OF CONTENTS

Introduction.....	3
Methodology.....	4
Results.....	6
Community Input Summary:	
HIV Response Plan Necessities.....	7
HIV Response Process.....	12
Participation in HIV Response Activities.....	15
Future Engagement.....	18
Additional Participant Feedback & Questions.....	19
Conclusion & Recommendations Summary.....	20
Appendix 1: Engagement Session Questionnaire	22
Appendix 2: Post-Session Survey.....	23
Appendix 3: Relevant Literature.....	24



Introduction

HIV remains a critical concern in the state of Washington. The US Ending the HIV Epidemic initiative identifies King County, WA as one of 48 counties that must be prioritized to reduce HIV incidence in the United States. In addition, more than half of Washington’s new HIV cases occur outside of King County, where HIV response efforts continue to be needed. Social and structural inequities persist and manifest in the disproportionate burden of HIV on communities including but not limited to men who have sex with men, transgender people, persons who inject drugs, and communities of color.¹ Community engagement in Washington’s HIV response remains vital, and it must include disproportionately affected and geographically representative populations in order to be successful.

In 2022, the Washington State Department of Health (DOH) initiated a community engagement program to conduct outreach to and engagement of communities disproportionately impacted by HIV for the purpose of delivering information on HIV surveillance activities, gathering input and feedback on the state’s HIV outbreak response plan, responding to questions and concerns, and developing recommendations for future engagement of these communities. More specifically, this program focused on engaging key populations in Washington state on the topic of HIV molecular epidemiology (ME) and cluster detection and response (CDR). Recognizing that DOH was already actively engaged in CDR without having conducted robust and CDR-specific community engagement, DOH partnered with an independent contractor to begin a community engagement process largely focused on educating community members about CDR and garnering their input on its role in the state’s HIV response plan. This report details the methods, findings, and recommendations resulting from this community engagement program.

This report is authored by Brian Minalga (independent contractor) with special thanks to DOH staff including Claire Mocha, Chelsey Kaasa, Jennifer Reuer, Steven Erly, Lydia Guy Ortiz, Vanessa Rojas, Vanessa Grandberry, Ray Harris, and—most importantly—the community participants whose contributions and dedication to ending the HIV epidemic in Washington state made this work possible.

¹ HIV/AIDS Epidemiology Unit, Public Health – Seattle & King County and the Infectious Disease Assessment Unit, Washington State Department of Health. HIV/ AIDS Epidemiology Report 2022, Volume 91.



Methodology

The primary aim of this community engagement project was to reach people living with HIV (PLHIV) and people from communities who, due to systemic oppression, marginalization, exclusion, disinvestment, and discrimination, are disproportionately affected by HIV in Washington state. The highest priority was placed on outreach to groups who have been historically overlooked in DOH's community engagement activities. Further recognizing that Public Health-Seattle & King County has conducted its own community engagement process for King County residents, this project was intentionally designed and marketed for Washingtonians living outside of King County. Though not exclusive or exhaustive, and recognizing that people have multifaceted identities and may fit into multiple categories, the following list summarizes the regions and demographic populations identified for outreach:

Regions

- Puget Sound (Whatcom, Skagit, San Juan, Island, Snohomish, and Pierce counties)
- Peninsula (Clallam, Jefferson, Kitsap, Grays Harbor, Mason, and Thurston counties)
- Southwest WA (Lewis, Pacific, Wahkiakum, Cowlitz, Clark, and Skamania counties)
- Central WA (Okanogan, Chelan, Douglas, Grant, Kittitas, Klickitat, and Yakima counties)
- Northeast WA (Whitman, Spokane, Lincoln, Ferry, Stevens, and Pend Oreille counties)
- Southeast WA (Benton, Franklin, Walla Walla, Columbia, Garfield, Asotin, and Adams counties)

Populations

- American Indian / Alaska Native / Indigenous / First Nations communities
- Asian American / Asian-Born communities
- Black / African American / African-Born communities
- Gay or bisexual men and/or men who have sex with men
- Hispanic / Latina/e/o/x communities
- Long-term survivors of HIV
- Native Hawaiian and other Pacific Islander communities
- People aged 50+
- People living with HIV (PLHIV)
- People recently diagnosed with HIV (within the last 3 years)
- People who inject drugs
- Queer communities
- Transgender and gender-diverse communities
- Women
- Youth (18-25 years old)

Engagement with these communities was envisioned as a series of ten interactive sessions which were scheduled to take place virtually (on Zoom) from September to December of 2022; participants were to register for one of the ten sessions. Each session was two hours long and consisted of a presentation from DOH, another presentation from the contractor, and a facilitated discussion designed to solicit input from participants on HIV response activities:

Topic	Lead Speaker(s)	Time
Welcome and Introductions	Brian Minalga (Contractor)	15 minutes
Overview of current HIV surveillance and response activities in WA (focus on CDR)	Claire Mocha, Chelsey Kaasa, Jennifer Reuer (DOH)	20 minutes
Issues and concerns with HIV CDR and molecular epidemiology	Brian Minalga	15 minutes
Brief reflections	Participants	5 minutes
Break	n/a	5 minutes
Facilitated engagement discussion	Participants with Contractor facilitating	50 minutes
Closing	Brian Minalga	10 minutes

The marketing strategy for these ten sessions included the following measures:

- Advertising on the [DOH website](#)
- Leveraging various DOH listservs and offices to promote the sessions
- Directly contacting (primarily via email) DOH-funded community-based organizations, syringe services providers, case managers, peer navigators, employee resource groups, state boards and commissions, and all DOH-Office of Infectious Disease staff with a request to promote the sessions among their clients and stakeholders—focusing especially on outreach to prioritized populations
- Identifying additional HIV-related and/or social-justice related organizations in WA and contacting them directly (primarily via email) to promote the sessions
- Conducting a modest social media campaign to promote the sessions
- Offering \$25 gift cards as a token of appreciation for each session participant
- Designing one of the ten sessions as a Spanish-language session and marketing it accordingly in Spanish

Sessions were designed for DOH staff to leave after the first 35 minutes to promote candid discussion among participants and the independent contractor. After each session, participants were asked to complete a brief survey to provide some demographic information and additional input to help assess the success of the sessions and plan for future DOH engagement activities.

Results

Potential participants registered for all ten community engagement sessions. Due to actual participant turnout, DOH held six out of the ten planned community engagement sessions. In total, DOH reached sixteen participants, with session size ranging from one to four participants each. Survey respondents reported hearing about the sessions through the following means:

1. **Email** (5 respondents)
2. **Local or state health department or community-based organization** (4 respondents)
3. **DOH/OID website** (1 respondent)
4. **Social media** (1 respondent)
5. **Other (open field)** (3 respondents)
 - a. "HIV Advocate Brian Minalga aka ROCKSTAR"
 - b. "WSPG meetings"
 - c. "coworker"

Table 1: Participant Characteristics

Characteristic	Number (Percent)
Residency	
King County	4 (36%)
Northeast WA	1 (9%)
Peninsula	2 (18%)
Southwest WA	4 (36%)
Age	
Person age 50+	4 (36%)
Youth (18-25 years old)	1 (9%)
HIV Status	
Person living with HIV	9 (82%)
Long-term survivor of HIV	4 (36%)
Race & Nationality	
American Indian/Alaska Native/Indigenous/First Nations	1 (9%)
Black/African American	3 (27%)
Person of color	2 (18%)
Immigrant/Refugee/Non-US Born	1 (9%)
Sexual Orientation & Gender Identity	
Gay or bisexual man (cis or trans) and/or man who has sex with men	6 (55%)
Queer	2 (18%)
Transgender, nonbinary, gender nonconforming, Two-Spirit	2 (18%)
Woman (cis or trans)	2 (18%)

Table 1 summarizes the characteristics reported by the eleven participants who completed the post-session survey (69% response rate). Note that all survey questions were optional; respondents may not have completed all questions.

Participants did not report membership to the following priority communities:

- Central WA, Puget Sound, Southeast WA

- Asian American, Native Hawaiian/Other Pacific Islander, Hispanic/Latina/e/o/x
- Person recently diagnosed with HIV (within the last 3 years)
- Person who injects drugs

All sixteen participants actively engaged during the sessions and provided input on HIV response activities in Washington state, including CDR. The following sections of this report summarize input received from participants during the sessions and through the post-session survey. Select quotes from session participants have been included.



Community Input Summary: HIV Response Plan Necessities

Participants were asked, “What must-have considerations need to be included in the WA state HIV Outbreak and Response Plan?” In response to this question, participants raised a range of necessary considerations that can be categorized into five major areas: transparency, informed consent, accounting for context, data security and privacy, and medication access.

Transparency

A primary necessity identified by participants was transparency from DOH with regard to HIV CDR and other related HIV response activities. Participants emphasized that the system of HIV response in Washington state, which includes DOH, is not currently transparent enough when it comes to:

- What information is collected from all people living with HIV
- What information is collected from people identified in HIV transmission clusters
- Why said information is collected
- How said information is used
- The legal rights and requirements associated with said information.

“One issue is that the health department is doing a lot of things that people just need to know about, and knowing about it would help address privacy concerns. But we don’t know about it because we haven’t heard from the health department about it. They need to educate the community.”

Participants felt that many of the community concerns expressed about molecular HIV surveillance and CDR would be satisfied with greater transparency. They noted that the lack of transparency raises suspicions about DOH’s intentions and exacerbates a legacy of medical distrust in the community. Participants expressed a vast willingness to participate in any efforts to end the HIV epidemic in Washington state, but that the lack of transparency erodes

trust in DOH and poses a barrier to the willingness of communities to collaborate with DOH. Furthermore, participants emphasized that the reasons for engaging in HIV molecular epidemiology (ME) and CDR must be readily understandable with measurable indicators for why it is important, how it is effective, how it is safe, and what the intended results are. Participants noted that there cannot be community buy-in without greater transparency.

“I can see how they would need more data to make cluster detection effective. I just had my own genetics done through Ancestry.com, and the more people who submit their data, the more information I get into my own ancestry. So I can understand that, and that’s not the problem. The problem is if you’re doing this behind people’s backs and not letting them know. All you have to do is tell me why this is important, and I’m on board. But you’re not letting us know, and that seems shady. That seems very deceptive—and purposely deceptive.”

To this end, participants shared specific ideas to improve transparency:

- DOH should detail in writing within the Washington State HIV Outbreak and Response Plan exactly how HIV response activities will be explained and broadcast transparently to communities. This detailed transparency plan should include information on how patients will be informed of any uses of their health and HIV data.
- The creation of a pamphlet or other public education tool so that the burden of explaining ME and CDR does not fall on medical providers to explain these concepts to each patient. Community education should include detailed information on why ME and CDR are important, how they’re effective, how they’re safe, and what the intended results are.
- Training for DOH-funded HIV organizations that mobilizes case managers and other staff to help educate communities and increase transparency around ME and CDR.

“There has to be a reason behind it. I joined studies and trials because there was a reason behind it. There was an end result. Well, we don’t have a clear end result that molecular HIV cluster detection and response is beneficial to anyone. They’ve been collecting these data for years, and yet they can’t show the results? The benefit? The cost analysis?”

Informed Consent

Some participants expressed dismay to learn that DOH is using HIV genetic information obtained from the medical care of Washingtonians living with HIV in order to conduct ME and CDR, and that this practice is being performed without the knowledge or consent of the patients from whom the information is garnered. Most participants were people living with HIV, and some questioned how their own medical appointments had contributed to DOH's database and activities without their knowledge or consent. While participants expressed support for any activities that contributed to better outcomes for people living with and affected by HIV in Washington state, they also described informed consent for the public health use of otherwise private medical information as "basic and fundamental." They felt that patients should at least be given the opportunity to understand what is being done with their medical information.

"As long as the patient is informed about how that information is going to be used, and about the security and privacy measures that will be enforced, I don't have a problem with it being collected at the doctor's office. Not having that information transmitted to a patient is unethical. They have a right to know that. We have a right to know."

Participants were divided on an idea that has been proposed in the national discourse on molecular epidemiology: the option for PLHIV to opt out of having their HIV genetic information used for ME, CDR, or any purpose other than their own personal medical care. Some participants saw the ability to decide what is done with their HIV genetic information as a fundamental component of their bodily autonomy and human rights, and that the decision of whether or not to use this information for public health purposes should therefore be theirs to make. These participants felt that an opt-out option would also encourage a healthy relationship between patients, doctors, and health systems, and they described not having an opt-out option as "forced" sharing of data that is tied to lifesaving HIV care.

"From a legal perspective, informed consent is probably one of the better tools in the kit. If the patient has the opportunity to understand what is being done with their information and is given the opportunity to opt out, then you have informed consent. Which is kind of like the basic legal framework across the board."

Other participants felt strongly that DOH and other public health actors need data to fulfill their obligation to protect public health at large, and that individuals have a responsibility to participate in this public health system—including by allowing their HIV genetic data to be used for public health purposes. One participant said that he could not support a public health system that allowed people to opt out, noting that there must be a balance between individual rights and public health, and

stating, "rights have responsibilities, and we have more to worry about than our own personal interests."

However, all participants, including those who did not support an opt-out option, agreed that people need to be informed about how their medical information is used, as well as

how it is protected. All participants agreed that informing patients of all uses of their medical data is non-negotiable, and that the WA State HIV Outbreak and Response Plan should outline how DOH plans to ensure that all PLHIV in WA know how their information is used.

Furthermore, most participants expressed willingness to have their own HIV data shared and used for public health purposes, but they acknowledged that many other PLHIV in their communities were not represented in these DOH sessions and, if given the opportunity, would likely not agree to having their HIV data shared. Participants raising this issue noted that the concerns of people not represented in these DOH sessions are valid and must be accounted for in WA's HIV response plans.

“Data should guide everything. We need good data, or we can't make good decisions. So I could not support having a process that allowed people to opt out. But you need to inform people. People have a right to know what is being done with their information.”

Accounting for Context

Participants continued to emphasize that their own individual views of ME and CDR do not represent the views of all priority populations in Washington state, and that DOH needs to account for variables that create different contexts in people's lives. Several participants noted that the community engagement process that is the subject of this report was inherently limited to the engagement of people with two hours of time to spare, and that the findings from this process likely overrepresent the perspectives of people who are comfortable speaking with DOH, discussing their own HIV status, and having information about their HIV shared and used for public health purposes. Participants found it important for DOH to account for the multifaceted contexts of privilege, oppression, and diversity, and to meet the needs of each community and each individual in the HIV response.

Participants highlighted people with mental health needs, people experiencing homelessness, people who are undocumented, and transgender people as groups who could be rendered particularly vulnerable to stigma, discrimination, and violence through ME and CDR. Participants noted that many priority populations have urgent needs such as medication access and safe housing, and they questioned DOH's investment in CDR when so many people living with and affected by HIV continue to struggle with basic needs. Participants suggested that DOH's efforts may be more effectively directed toward addressing these basic needs rather than conducting complex molecular analyses of HIV transmission dynamics.

“I'm speaking from a place of privilege here. For me...I'm like yeah, go ahead and take my information! But I completely see how this would not be OK for some people. As far as looking at the populations we're serving, it's really important to consider how things need to be from their perspective.”

“I’m meeting my clients where they are and trying to help them in any way they need me and to protect them from predatory systems. A lot of my clients would absolutely freak out at the thought of this information being out there. And I have a moral obligation to inform my clients of all aspects of their care. Personally, I have lived so openly about my status, there is nothing anyone can say or do to hurt me. So for me, this isn’t about me—it’s about my clients.”

Almost every participant raised stigma as a contextual factor that DOH should address with urgency and take into account when planning HIV response activities including CDR. They noted that safety remains a very real issue for PLHIV—especially those experiencing various forms of stigma and discrimination related to immigration status, housing status, mental illness, and racism. Several participants requested a greater emphasis on HIV criminalization in DOH’s HIV response planning, recognizing that the threat of criminalization—even under Washington’s recently revised HIV criminal code—prevents people from getting tested, accessing care, and using prevention methods like PrEP. These participants added that there are special

criminalization and deportation concerns for people who are undocumented, and that DOH must account for this context in HIV response planning. Participants called for DOH to include a comprehensive plan to completely decriminalize and destigmatize HIV in the state’s HIV Outbreak and Response Plan.

Data Security and Privacy

Participants raised data security and privacy as primary concerns with HIV CDR. They related that if Washingtonians had clear and specific assurances that HIV molecular data were kept secure and private, then this would be less of an area of concern. More specifically, participants defined two criteria for secure and private HIV molecular data:

1. They should be available exclusively to people working directly with these data on specific HIV response activities and
2. They should be used exclusively in HIV response activities that are proven to be measurably effective in improving health outcomes for PLHIV and reducing HIV incidence.

Participants further specified that HIV molecular data should not be made available for research projects or other activities that are not intended to directly improve HIV-related outcomes in the state of Washington (e.g. theoretical concepts or mathematical models). In this regard, participants supported DOH’s indefinite pause on sharing HIV molecular data with external researchers.

“If these systems are going to work, privacy concerns need to be addressed before you try to implement the system. It doesn’t make sense to implement the system before addressing the privacy concerns.”

Participants identified the necessity to include a detailed data security and privacy plan within the WA HIV Response Plan, including details on how DOH protects the data privacy of individuals involved in any potential HIV transmission clusters or outbreaks. They elaborated that the data security and privacy plan should specify the safeguards in place for ensuring that Washington’s HIV molecular data can never be shared with law enforcement anywhere and for any reason, and that it can never be used in criminal/legal

proceedings against PLHIV. They added that DOH’s HIV Response Plan should account for system error and human error, acknowledging that although DOH reports never having had a data breach, DOH must have a contingency plan in place to account for potential future errors or breaches. Participants felt that it was unreasonable to proceed with HIV ME and CDR before these privacy concerns are addressed.

Medication Access

Participants identified a high-priority issue to include in the WA HIV Response Plan that is not limited to HIV ME: medication access. Specifically, participants noted that many Washingtonians continue to experience barriers to accessing antiretroviral therapy, post-exposure prophylaxis, and pre-exposure prophylaxis (HIV medications). They insisted that DOH include details in the HIV Response plan outlining:

- how DOH will ensure that HIV medications will be made available to every Washingtonian in every part of the state,
- how DOH will make Washingtonians aware of their access to HIV medications, and
- how DOH will work to destigmatize the use HIV medications.

Community Input Summary: HIV Response Process

Participants were asked, “When an HIV cluster or outbreak is identified in Washington state, what should happen?” Participants responded to this broad question, and then they were guided through a series of related discussion questions:

- What should be done for the people in the cluster/outbreak?
- What should be done to prevent it from growing?
- Who should be informed?
- What information should be shared about it?
- How should information about it be communicated?

The Washington State HIV Response Plan Community Engagement Report
DOH 150-225 (JULY 2023 ENGLISH)

To request this document in another format, call 1-800-525-0127. Deaf or hard of hearing customers, please call 711 (Washington Relay) or email civil.rights@doh.wa.gov.



Participants' input on the HIV response process fell into two primary categories: service delivery and communications management.

Service Delivery

Participants emphasized that when an HIV transmission network is identified, DOH's focus should be on delivering needed services to people in the network. They identified the following examples of services that could be offered, noting that the type of services offered should be tailored to each situation:

- Conducting interviews with people in the HIV transmission network to better understand their needs
- HIV testing, including self-testing
- Housing and shelter services
- Sexual health services
- Domestic/intimate partner violence services
- Needle exchange
- Addiction support services
- Mental health
- Medication access, including HIV treatment, PEP, and PrEP
- Social and emotional support, and
- Case management.

"I think this is something that was missing from the DOH presentation. They talked a lot about what's being done with the data, but not what's being done with boots on the ground. I didn't realize that there was any kind of failure going on that necessitated us having to map [HIV] molecularly. So, I think what's missing there is what kind of services are being provided immediately to individuals."

With regard to medication access (including ART, PEP, and PrEP), participants shared that DOH must ensure that cost is not a barrier. One participant noted that ART cost remains a serious issue for PLHIV in WA, and that DOH needs to do a better job of offering options and solutions—including linking people to community-based organizations and drug assistance programs. Participants also highlighted PEP as a potentially underutilized tool and suggested that DOH works to increase PEP uptake within HIV transmission networks.

"We have infectious disease specialists who still don't tell their clients about ASOs and all the services we offer. We have clients who come to us and say they've sold everything they have with nothing left—just to get their meds—when we could have helped them."

A major theme that surfaced as part of the service delivery discussion was the importance of social and emotional support for people living with and affected by HIV, including those identified in HIV transmission networks. Participants emphasized the difference that social support can make in the lives of PLHIV, and they strongly recommended that DOH offers linkage to *continuous* support—not

only around the time of diagnosis. Participants included examples of social and emotional support such as case management, ongoing wellness check-ins and follow-up at regular

intervals, proactively offering services that clients may not be aware of, and peer support groups (i.e. with other PLHIV).

“When I was diagnosed, I was so ashamed, I didn’t accept any services. I even went to a counselor who said I should do this and that, because I would have a tremendous amount of issues later if I didn’t take advantage of the services available. And eventually I did, but I didn’t at first, and it cost me a lot. It wasn’t that the counselor wasn’t good at explaining it. It’s just that I felt so ashamed. So that emotional impact is very important. The health department should be prepared for a wide range of different kinds of responses from people who are recently diagnosed.”

“If I think back to when I was first diagnosed, in that room, I didn’t want you to give me all the molecular stuff. I really just wanted to not be scared that I’m about to die. Think about being a person of color or a woman or transgender. You’re going up against a lot. Your family may or may not accept you, or your community. You’re pretty much by yourself. So people are still battling all these things, and you want to do all this molecular analysis on them? It doesn’t work that way. The response plan really needs to consider community involvement.”

Communications Management

Participants provided recommendations on how DOH should manage communications around identified HIV transmission networks. Participants recommended that DOH focus on communicating with the people involved in transmission networks as their main communications priority—especially in terms of service delivery. The second layer of communications should prioritize public health actors who are tasked with using information about an identified transmission network to directly address the needs of the people in said network. Participants specified that this second layer of communications priority may also include community-based organizations and venues that are part of the affected community, recognizing that grassroots mobilization plays a major role in public health response.

Participants were somewhat divided on a third layer of communications priority: the media and broader public. Some participants felt that the media and broader public should not be informed at all about the identification of an HIV transmission network, suggesting that doing so could cause more harm than good. Other participants felt that DOH must have some role in media outreach to control “inevitable” messaging about identified transmission networks, and to ensure that any public discourse is evidence-based and non-stigmatizing. These participants recommended that any information shared publicly about HIV transmission networks should be general in nature, such as the number of people impacted and the general conditions associated with transmission. They suggested that public information about HIV transmission networks should not include information such as the neighborhoods involved or other information that could stigmatize or otherwise harm the people in the HIV transmission network or the broader communities to which they belong.

“I don’t know about going out there and informing the general public that ‘there’s an HIV outbreak among itinerant farm workers in Yakima.’ No, there’s no reason to do that. It’s not like SARS where anyone can get it in the general public. I think it would be important to go into the specific community where the outbreak is taking place, like an encampment of people who are homeless, and make everyone aware. That’s essential. But having information leak out to the entire state of Washington doesn’t seem to serve a purpose.”

Participants added that DOH should conduct community engagement to ensure that its own language is culturally responsive and non-stigmatizing. Furthermore, participants noted that DOH’s language should not only be non-stigmatizing, but also “warmer” such that it communicates compassion for those affected and empathy for community members who are not scientists. Participants also emphasized that context matters, noting that people in small towns have different communications needs compared to people in Seattle—especially pertaining to privacy, safety, and stigma. Finally, participants suggested that DOH invest more into regular HIV education for the general public that destigmatizes HIV and HIV prevention. They felt

that broader HIV education would better prepare the public to receive news of a potential HIV outbreak with less stigma. To this end, participants recommended a DOH-sponsored HIV education social media campaign, specifically naming TikTok as a platform that DOH should explore.

“There has to be a certain amount of outreach from DOH trying to counteract any fears in the broader community. Be proactive by saying there could be an outbreak, and maybe you reinforce the basic information on what HIV is and how it spreads. Reinforcing that might calm the community fears so we can go forward with testing and data collection.”

Community Input Summary: Participation in HIV Response Activities

Participants were asked the following questions about their willingness to participate in HIV response activities:

- What would prevent you from wanting to be part of HIV cluster/outbreak response activities?

The Washington State HIV Response Plan Community Engagement Report
DOH 150-225 (JULY 2023 ENGLISH)

To request this document in another format, call 1-800-525-0127. Deaf or hard of hearing customers, please call 711 (Washington Relay) or email civil.rights@doh.wa.gov.



- What do you think are the benefits of HIV cluster/outbreak response activities?
- What would make you want to participate in HIV cluster/outbreak response activities?

This section summarizes participants’ perspectives on barriers and facilitators to community participation in HIV cluster/outbreak activities.

Barriers

Stigma and discrimination were perceived as a major barrier to participation in HIV cluster/outbreak response activities. Participants expressed concerns about how HIV ME and CDR could exacerbate existing forms of stigma and discrimination, including negative perceptions of PLHIV, HIV criminalization, prejudice against communities that are disproportionately affected by HIV, racism, homophobia, and bias-based violence.

Participants also expressed fears that data from HIV ME/CDR activities could result in political repercussions for PLHIV and communities disproportionately affected by HIV in Washington state—for example, legislation that would reduce funding for HIV services and/or fuel social and political hate against populations represented in HIV transmission networks. Participants recommended that DOH explicitly address its plans for reducing the potential for stigma in HIV ME and CDR, including how these data could or could not be used in criminal/legal proceedings against PLHIV. Participants also recommended that DOH work to reduce its own stigmatizing language, noting that even the terms “outbreak” and “HIV cluster” can be offensive. They suggested more neutral terms such as “HIV occurrence” and “incidence,” although some participants felt that DOH should avoid language that could be perceived as too scientific, jargony, or scary. Participants recommended that DOH conduct community consultations to revise language appropriately.

“I think something that would prevent me from wanting to be part of these activities would be stigma—in a big way. Maybe that’s not something that I want anyone to know about my life. Maybe people finding out that about me might be dangerous for me.”

“Language is important, and in this field, there has been so much negative, stigmatizing language thrown at us—everything from *deviants* to *dirty*. DOH needs to think about that. But that’s the thing—if they’re not telling anyone that they’re doing this, then they can use whatever language they want! Because you’re using this terminology that hasn’t been brought through the scrutiny of the public. We’re talking about people—people who are going through what may be the most heartbreaking moment of their lives. So there needs to be more sensitivity around the language. I am not an outbreak. I am not a cluster.”

“The health department talked about an HIV outbreak among Latino gay and bisexual men in San Antonio. Even if you didn’t know the names of each individual in that cluster, it still had the potential to stigmatize the community, being described as a “cluster” and having an HIV outbreak. So stigma plays a role not just for individual people, but at the community level too.”

Participants also reemphasized two necessities they had previously identified: data privacy and DOH’s transparency. They felt that concerns about data privacy posed a major barrier to community participation in CDR activities—for example, concerns that someone’s personally identifiable HIV or other medical information could be publicly shared or leaked. They repeated that the lack of transparency about HIV ME and CDR causes serious community distrust, and that communities would remain reluctant to cooperate with HIV response activities so long as this lack of transparency about what DOH does with patient data persists.

Participants also felt that HIV ME and CDR run the risk of dehumanizing people depending on how these response activities are conducted. For example, participants worried that the molecular approaches to HIV response might favor the treatment of people as data points or subjects of academic intrigue rather than human beings with complex emotions and needs. They expressed that the potential dehumanizing effects of these activities would pose a major barrier to community willingness to participate, and they recommended that DOH put people first in its response to HIV, including trainings for all staff in social, emotional, and cultural sensitivity.

“I can speak specifically about being a Black woman: Tuskegee is still something that traumatizes us. And what happened in Tuskegee? They didn’t tell the people in that study what was really going on. With molecular analysis, they’re not telling us what’s going on. It’s scary. People are still traumatized about something that happened decades ago—and why? Because it’s still happening today. They’re still not telling us what they’re doing with our data and our medical information.”

Finally, participants identified the lack of community representation in HIV response activities as a barrier to community participation. They recommended that DOH both hire and partner with people representative of priority communities to obtain community buy-in and conduct effective HIV response activities.

“If someone contacted me and said I was part of a cluster, and if I come in and I don’t see people who look like me, I’m not staying. And not just the color part. There needs to be trans people in the space.”

Facilitators

Almost every participant said that they would be more willing to participate in molecular HIV response activities if they better understood how these activities contributed to meaningful progress in the overall HIV response. Participants expressed a great deal of altruism and desire to contribute to an end to the HIV epidemic, but they felt that DOH has not adequately explained the benefits of HIV ME and CDR. Participants suggested that DOH better explain the specific aims and outcomes of HIV ME/CDR and contextualize these activities in terms of specific and measurable benefits, relative to non-molecular responses to HIV. They said that they would be much more willing to participate if DOH could explain how HIV ME

directly meets the needs of people living with and affected by HIV in Washington state. Participants also expressed disappointment that DOH has not more actively engaged the community in HIV response activities, reiterating how a lack of transparency around HIV ME not only exacerbates distrust, but also misses an opportunity to mobilize communities to help achieve public health goals. Participants added that, in contrast to stigmatizing language, affirming and engaging language would serve as a facilitator to participation in HIV response activities.

“I am confused about the advantage of molecular analysis. I don’t understand how it is better than speaking with people with an HIV diagnosis and their partners and offering services to communities. Shouldn’t you just outreach to everyone who is out of care no matter what strain of HIV they have? I would also like to know the time and financial costs of molecular analysis in relation to other HIV activities. Is molecular analysis taking resources away from other HIV services?”

“If I knew how these activities would benefit me in the long run, and everyone in the cluster. If I could participate to help me and somebody coming after me, that’s what would make me want to participate.”

“Think about how we talk positively about COVID-19 vaccines. We say things like *uptake, engagement, investment*. Use positive words that aren’t stigmatizing. This is what the planning councils and CABs could really come up with—if they knew about it.”

“If this sort of information would actually help to bring a cure sooner, then that would be a motivating factor.”

“I could be part of the...a piece of the help to be a part of this, you know what I mean? But we don’t get options like that—nobody comes to us to be like hey, would you like to participate in something that might help people? Ya’ll just have our information on a list, or you’re just doing what you’re gonna do with it, and I don’t know nothing about it. Which means that even if I want to know or work on it, I don’t have the opportunity.”



Community Input Summary: Future Engagement

Participants were asked, “In the future, how should the health department engage us, the community, to provide input into the HIV Outbreak & Response Plan and related activities?” Participants expressed a great deal of enthusiasm for continuing to be involved, and many shared their contact information in the post-session survey to be engaged directly in the future. The following is a summarized list of suggestions that participants provided for future engagement:

- Present findings from this 2022 initiative back to the community.
- Inform the community how specific input from this 2022 initiative is being incorporated and utilized in DOH’s HIV response plan.
- Share a draft of the HIV response plan online as well as through a presentation or series of presentations, and invite feedback to incorporate before finalizing the plan.
- Hold additional presentations, meetings, conversations, and town halls on this topic.
- Conduct a more comprehensive community engagement campaign on this topic that includes HIV planning councils, community-based organizations, providers, county-level groups and steering committees, syndemic planning groups, the kiki ballroom scene, community-embedded venues and events, and other HIV-affiliated groups and organizations in the state.
- Improve promotion and marketing of community engagement sessions and initiatives.
- Conduct one-on-one key informant interviews to complement the sort of information obtained from focus group settings.
- Continue to focus on outreach and engagement outside of King County, where many Washington residents feel neglected by DOH.
- Hold community input sessions without DOH present at all, and market these sessions as by and for community without marketing DOH’s involvement.
- Engage by directly supporting people with urgent needs who do not have the time or capacity to offer input and recommendations to DOH. Recognize that providing medicine, care, food, housing support, and other basic needs is also a form of community engagement.
- Offer more compensation than \$25 for community input, and include people working at DOH-funded agencies as eligible to receive compensation.
- Form a state HIV advisory board modeled after Louisiana’s advisory board discussed during these sessions, and ensure that it has representation from Eastern Washington.



Community Input Summary: Additional Participant Questions

Session participants included additional questions for DOH to consider and respond to in future community engagement initiatives:

- What purpose does HIV molecular analysis serve in Washington state?
- Are HIV genetic data kept separate from the identifying information of the person to whom they belong?
- What IT/cybersecurity protocols and procedures are in place to ensure the security of these data? Are these data kept in an air-gapped network? Are they stored in any kind of "cloud" storage or in an on-premise datacenter? Who manages and owns the datacenter?
- What happens when a person living with HIV moves states? Does their HIV data get transferred from one state to another? How does their information link between databases?
- Would it be possible for law enforcement to access people's HIV-related information that DOH collects and uses?
- What exactly are the current rights and rules pertaining to HIV criminalization in Washington state? Could HIV genetic data be used in HIV criminalization cases in WA?
- If people living with HIV in Washington state want information about the HIV transmission network that they belong to, how can they access that information?
- When CDC began requiring states to conduct molecular HIV analysis, did the health departments go back and access all genetic samples from everyone in the state whose information was available, or are they only working with genetic sequences from new HIV diagnoses?
- Does a person's HIV genetic information change over time, or do you only need to perform the genome sequence once because it stays relatively the same?
- What is the accuracy of HIV molecular analysis comparing two sequences of HIV to each other?
- What sample size of HIV sequences is required to build an accurate genetic tree and minimize errors?
- If people were given the opportunity to opt out of having their HIV molecular data used for CDR, how much would that undercut the efficacy of molecular analysis by not having everyone's sequence?
- Is DOH using an independent third party to evaluate the utility and error margins of the data being used in CDR activities?

- What is the typical time delay involved in molecular analysis? Does it really give the health department enough time to intervene before more people acquire HIV in a cluster?

“As I understand it, molecular analysis isn’t something DOH can unilaterally stop, but I hope that they can be a leader in how they handle this data moving forward. I have a hard time believing that this type of data analysis can be more meaningful than good-old-fashioned contact tracing and boots on the ground, actually delivering comprehensive services to people in need. And I feel that money spent towards actually delivering those services would serve the at-risk populations better.”

Conclusion & Recommendations Summary

Washingtonians are committed to ending the HIV epidemic. Those who participated in this community engagement program are passionate, resourceful, and ready to engage. They are already involved in the HIV response at the local and state levels, and they want to be more meaningfully included in DOH’s plans and activities. They especially want to be informed of DOH’s goals, objectives, and processes, and they would like to be further consulted about HIV molecular epidemiology and cluster detection and response. Washingtonians are willing to partner and collaborate with DOH in the shared mission for better health and wellness for people living with and affected by HIV—but their conditions for true collaboration include trust and meaningful engagement. These members of the community represent Washington’s greatest resource for ending the HIV epidemic, and this DOH initiative represents the very beginning of a process to harness that collaborative potential.

This report ends with a condensed summary of recommendations garnered through this 2022 community engagement initiative. DOH’s task will be to operationalize these recommendations and continue its process to engage the community in Washington state’s HIV response.

Condensed Summary of Recommendations

- Make the findings of this report available to the participants from this community engagement initiative and the broader community. Define DOH’s process for incorporating input garnered from this community engagement initiative into the WA state HIV response plan.
- Share a draft of the HIV response plan online as well as through a presentation or series of presentations, and invite feedback to incorporate before finalizing the plan.
- Design a resource or series of resources (e.g. videos, infographics, slides, etc) to simply, clearly, concretely, and measurably demonstrate the need for HIV molecular epidemiology and cluster detection and response, relative to other HIV response activities.

- Create a comprehensive plan to inform all PLHIV in WA state how their HIV data are used for molecular epidemiology and cluster detection and response. Involve providers, CBOs, steering committees, key community informants, and other stakeholders in the creation of this plan.
- Publicly define the data security and privacy measures that protect HIV molecular data, incorporating the criteria identified on page 11 of this report.
- Conduct an evaluation including a representative cross-section of PLHIV in WA and an independent third party to determine the acceptability and feasibility of offering PLHIV the option to opt out of having their HIV genetic information used for public health purposes.
- Conduct one-on-one key informant interviews to complement the sort of information obtained from focus group settings.
- Hold community input sessions without DOH present at all, and market these sessions as by and for community without marketing DOH's involvement.
- Create an anonymous survey to gather additional input on HIV ME/CDR from Washingtonians who may not be willing or able to participate in live sessions.
- Offer more compensation than \$25 for community input, and include people working at DOH-funded agencies as eligible to receive compensation.
- Form a state HIV advisory board modeled after Louisiana's advisory board discussed during these sessions, and ensure that it has representation from Eastern Washington.
- Significantly expand the mobilization of community-based organizations (CBOs) and committees to engage the community in HIV response activities (e.g. conduct in-person presentations and town halls hosted in equal partnership with CBOs).
- Invest in more effective outreach, marketing, and promotion of DOH's community engagement initiatives through relationships with community partners as well as online, including social media.
- Develop a comprehensive HIV incidence communications plan that prioritizes people involved in HIV transmission networks, then public health actors directly responding to HIV transmission networks, and then the public (see pages 13-14 of this report).
- Commit to destigmatizing HIV through a statewide HIV education campaign, thoughtfully and creatively designed for the general public.
- Consult with communities of PLHIV to revise the terms *outbreak*, *clusters*, and other DOH language and terminology related to HIV.
- Create a resource (e.g. infographic, social media campaign, video, etc) that explains the current HIV criminal law in WA state and how HIV ME/CDR could or could not be factors in criminal/legal proceedings against PLHIV, focusing especially on PLHIV who are undocumented and/or belong to other highly policed and surveilled communities. Also include DOH's role, even if none, in efforts to further decriminalize HIV in WA state.
- Steward DOH's resources to prioritize the most urgent needs of people living with and affected by HIV (i.e. testing, medication access, housing, food, mental health services, needle exchange, social and emotional support, sexual health, case management, etc).

- Create and implement a plan to make HIV treatment and prevention medications available and accessible to every person in Washington state.
- Hire and partner with people representative of priority communities to obtain community buy-in and conduct effective HIV response activities.
- Create an FAQ page on the DOH website, based on the questions on page 19 of this report, and include educational media (e.g. videos, infographics, slides, etc) on this FAQ page to better inform communities on how DOH uses HIV molecular epidemiology and cluster detection and response.

The Washington State HIV Response Plan Community Engagement Report
DOH 150-225 (JULY 2023 ENGLISH)

To request this document in another format, call 1-800-525-0127. Deaf or hard of hearing customers, please call 711 (Washington Relay) or email civil.rights@doh.wa.gov.





Appendix 1: Engagement Session Questionnaire

The questionnaire below was used during all six community engagement sessions to facilitate community input into the Washington State HIV Outbreak & Response Plan and related HIV response activities.

1. What must-have considerations need to be included in the WA state HIV Outbreak & Response Plan?
2. What would prevent you from wanting to be part of HIV cluster/outbreak activities?
3. What do you think are the benefits of HIV cluster/outbreak activities? What would make you want to participate?
4. When an HIV cluster or outbreak is identified here in WA, what should happen?

What should be done for the people in the cluster/outbreak?

What should be done to prevent it from growing?

Who should be informed?

What information should be shared about it?

How should information about it be communicated?

5. In the future, how should the health department engage us, the community, to provide input into the HIV Outbreak & Response Plan and related activities?
6. What additional feedback or questions do you have?



Appendix 2: Post-Session Survey

The survey below was offered to all session participants at the end of each session as an optional forum to provide anonymous feedback.

1. Please select the region of the state you live in. (Choose one)
 - a. Central (Okanogan, Chelan, Douglas, Grant, Kittitas, Klickitat, and Yakima counties)
 - b. King County
 - c. Northeast (Whitman, Spokane, Lincoln, Ferry, Stevens, and Pend Oreille counties)
 - d. Peninsula (Clallam, Jefferson, Kitsap, Grays Harbor, Mason, and Thurston counties)
 - e. Puget Sound (Whatcom, Skagit, San Juan, Island, Snohomish, and Pierce counties)
 - f. Southeast (Benton, Franklin, Walla Walla, Columbia, Garfield, Asotin, and Adams counties)
 - g. Southwest (Lewis, Pacific, Wahkiakum, Cowlitz, Clark, and Skamania counties)

2. Please choose the demographic labels you identify with. (Select all that apply)
 - a. American Indian / Alaska Native / Indigenous / First Nations communities
 - b. Asian American / Asian-Born communities
 - c. Black / African American / African-Born communities
 - d. Gay or bisexual men and/or men who have sex with men
 - e. Hispanic / Latina/e/o/x communities
 - f. Long-term survivors of HIV
 - g. Native Hawaiian and other Pacific Islander communities
 - h. People aged 50+
 - i. People living with HIV (PLHIV)
 - j. People recently diagnosed with HIV (within the last 3 years)
 - k. People who inject drugs
 - l. Queer communities
 - m. Transgender and gender-diverse communities
 - n. Women

3. What questions, concerns, thoughts, or suggestions do you have about our work in HIV cluster detection and response or HIV outbreak response planning?
4. How would you like the health department to continue to engage you about these topics?
5. Anything else you'd like to share?
6. How did you hear about the session? (Choose all that apply)
 - a. Social media
 - b. Email
 - c. OID website
 - d. Local or state health department or community-based organization
 - e. Other (open field):



Appendix 3: Relevant Literature

Below is a list of citations collected as part of the contractor's literature review for this community engagement initiative. This list can be used for future reference as the Washington State Department of Health (DOH) plans future community engagement initiatives focused on HIV cluster detection and response. DOH may also consider this list a living document and add to it as the field of HIV cluster detection and response continues to evolve.



Barrett DH et al (2022). "Stories, Stigma and Sequences: HIV Cluster Detection and Response Activities Through a Narrative Ethics Lens. Narrative Ethics in Public Health: The Value of Stories. Public Health Ethics. https://doi.org/10.1007/978-3-030-92080-7_7

Edwin Bernard et al (2020). "We are People, Not Clusters!" AJOB. <https://doi.org/10.1080/15265161.2020.1809550>

Mara Buchbinder, Eric Juengst, Stuart Rennie, Colleen Blue & David L. Rosen (2022): "Advancing a Data Justice Framework for Public Health Surveillance," AJOB Empirical Bioethics, DOI: 10.1080/23294515.2022.2063997

The Washington State HIV Response Plan Community Engagement Report
DOH 150-225 (JULY 2023 ENGLISH)

To request this document in another format, call 1-800-525-0127. Deaf or hard of hearing customers, please call 711 (Washington Relay) or email civil.rights@doh.wa.gov.



CDC (2020). “Meeting Summary: Responsible Use of HIV Cluster Data for Public Health Action: Amplifying Benefits, Minimizing Harms.”

<https://www.cdc.gov/hiv/programresources/guidance/cluster-outbreak/responsible-use.html>

Center for HIV Law and Policy (2019). “Is Molecular HIV Surveillance Worth the Risk?”

<https://www.hivlawandpolicy.org/resources/hiv-molecular-surveillance-worth-risk-center-hiv-law-and-policy-2019>

Liza Dawson et al (2020). “Addressing Ethical Challenges in US-Based HIV Phylogenetic Research.” *Journal of Infectious Diseases*. <https://doi.org/10.1093/infdis/jiaa107>

Golden, Matthew et al (2019). “Outbreak of Human Immunodeficiency Virus Infection Among Heterosexual Persons Who Are Living Homeless and Inject Drugs — Seattle, Washington, 2018.” *MMWR*.

Martha Kempner (2019). “New Study Triggers Concerns Over Use of Molecular HIV Surveillance.” *TheBodyPro*. <https://www.thebodypro.com/article/concerns-over-use-of-molecular-hiv-surveillance>

Kerani R (2022). “Data Driven Messaging to Increase Participation in HIV Cluster Detection and Response.” 2022 STD Prevention Conference. <https://cpb-us-e1.wpmucdn.com/sites.northwestern.edu/dist/e/6539/files/2022/11/Data-driven-messaging-to-increase-participation-in-HIV-cluster-detection-and-response.pdf>

Louisiana Office of Public Health STD/HIV/Hepatitis Program (2021). “HIV Cluster and Outbreak Detection and Response Plan.” <https://louisianahealthhub.org/wp-content/uploads/2021/11/Louisiana-HIV-Cluster-Outbreak-Detection-and-Response-Plan-10.2021.pdf>

Sanjay Mehta, Cynthia Schairer, and Susan Little (2019). “Ethical Issues in HIV Phylogenetics and Molecular Epidemiology.” *Current Opinion in HIV and AIDS*. https://journals.lww.com/co-hivandaids/Abstract/2019/05000/Ethical_issues_in_HIV_phylogenetics_and_molecular.11.aspx

Stephen Mollidrem, Anthony Smith, and Alexander McClelland (2022). “Predictive analytics in HIV surveillance require new approaches to data ethics, rights, and regulation in public health.” <https://www.tandfonline.com/eprint/XSSMPVDC4QY52HKE2TB3/full?target=10.1080/09581596.2022.2113035>

Murphy T (2020). “What Exactly is Molecular Surveillance –and Why are HIV Advocates Freaking Out Over It?” *TheBody*. <https://www.thebody.com/article/hiv-molecular-surveillance>

NASTAD (2022). “Cross-Jurisdictional Data Sharing: Legal, Practical, and Ethical Considerations for Improved Infectious Diseases Cluster Response.” <https://nastad.org/resources/cross-jurisdictional-data-sharing-legal-practical-and-ethical-considerations-improved>

Positive Women’s Network-USA & AIDS United (2020). “AIDS United’s Position on Using Molecular HIV Surveillance to Track HIV Transmission Networks” and “Open Letter to the CDC: Networks of People Living with HIV Demand a Moratorium on Molecular HIV Surveillance.” <https://www.pwn-usa.org/aids-uniteds-position-on-using-molecular-hiv-surveillance-to-track-hiv-transmission-networks/>

President’s Advisory Council on HIV/AIDS (2022). “Resolution on Molecular HIV Surveillance and Cluster Detection and Response.” HIV.gov. <https://www.hiv.gov/federal-response/pacha/about-pacha>

Diana Tordoff et al (2022). “Lessons Learned from Community Engagement Regarding Phylodynamic Research with Molecular HIV Surveillance Data.” SocArXiv. <https://doi.org/10.31235/osf.io/52fy8>

Trejo A and McClelland A (2021). “Molecular HIV Surveillance: A Global Review of Human Rights Implications.” <https://www.hivjusticeworldwide.org/wp-content/uploads/2021/10/HJWW-MHS-Paper-English-Final.pdf>

Wood BR, Stekler JD. “Baseline HIV genotype drug resistance testing: is it time for more or less?” AIDS. 2022 Aug 1;36(10):1449-1451. doi: 10.1097/QAD.0000000000003228. PMID: 35876702.