

## **DOH Community Collaborative Session Summary**

August 16, 2023 | 3:30 pm – 5:00 pm PT

### **Welcome and Introduction**

Todd Holloway, Community Collaborative Thought Partner and Facilitator of the Session, welcomed Community Collaborative members to the meeting. Meeting attendees introduced themselves via the Chat.

### **Accessibility & Zoom Navigation**

Tom Dineen, KAI Tech Facilitator, reviewed Zoom features and explained how to seek tech/language assistance during the meeting, if needed.

### **Land Acknowledgement and Overview of Agenda**

Todd read the Land & Labor Acknowledgement (see slides of the meeting for details) and reviewed the Session agenda.

### **DOH Proposed Legislative Decision Packages and Agency Request Legislation**

Kelly Cooper, DOH Legislative Director, shared the following information regarding bills for the 2024 and 2025 legislative sessions.

#### **Timeline for the 2024 Legislative Session**

- DOH develops budget requests and legislative agenda from May through July 2023
- DOH engages community and partners throughout August 2023
- DOH holds partner webinar on August 28<sup>th</sup>, 2023
- DOH's 2024 proposals are due to the Governor's Office on September 13<sup>th</sup>, 2023
- 2024 Legislative Session begins on January 8<sup>th</sup>, 2024
- End of Legislative Session is March 7<sup>th</sup>, 2024

#### **Preliminary Agency Request Legislation for 2024**

- Uniform Facilities Frames (SB 5271/HB 1434): DOH has established a standard framework for facilities enforcement based on acute care and psychiatric hospital laws. However, there is no such framework for other healthcare facilities regulated by the Department of Health. Under current law, the department's only compliance option is to suspend or revoke a facilities license in response to a violation. This proposal creates a uniform framework for all health facilities including intermediate enforcement tools and giving the department the ability to work with facilities to address repeat violations quicker. The bill also adds enforcement tools that allow the department to take swift action when a situation poses immediate risk to the public. This proposal aims to increase patient safety and facility compliance, while ensuring continued access to care.



- Standing Orders (new proposal): This proposal is for agency request legislation that gives clear statutory authority to the Secretary of Health to issue standing orders under state law. This would allow for increased access to immunizations, testing, and other services with increased agility for both routine and emergency public health needs.

Kelly invited everyone to attend the webinar on August 28, 2023 and provide input.

### **Preliminary Decision Package Proposals**

The following are programs for which DOH is asking for investments:

- Care-A-Van
- Outward-facing media campaign
- Adult immunizations
- Sustaining our Care Connect Washington program
- Implementing PEAR (Pro-Equity Anti-Racism) initiative and community compensation
- Health Equity Zones (HEZ) grant initiative
- Investments in Information Technology, including Informatics & Public Health Technology
- Investments in our Healthcare Enforcement and Licensing Management System (HELMS)
- Supporting critical professions: Agency Affiliated Counselors & Home Care Aides
- Rural Health Workforce
- Implementation of the 988 Behavioral Health Helpline
- Uniform Facilities Framework
- HEAL (Healthy Environment for All) Act implementation
- Credentialing, including reducing barriers to getting licensed and improving the licensing process
- Water Reuse in Buildings

### **Timeline for the 2025 Legislative Session**

- DOH programs bring concepts, both budget requests and legislative proposals, for the 2025 legislative session forward in early September 2023
- DOH will begin engaging community for initial feedback on 2025 proposals in early October 2023
- DOH will begin engaging community again in Mid-March 2024 for the 2025 Legislative Session

Kelly explained that DOH plans to engage the community and have deeper conversations earlier for the 2025 legislative session. Kelly again welcomed all to attend the webinar on August 28, 2023, which will be open to the public.

For those who are interested to attend the webinar, please contact Joel Jordan at [joel.jordan@doh.wa.gov](mailto:joel.jordan@doh.wa.gov).



## Diversity in Clinical Trials and Historical Context: [Second Substitute House Bill 1745](#)

### Historical Context

Cyril Walrond, Community Collaborative Thought Partner, highlighted the need and purpose of this section and introduced Thought Partner Kathleen Wilcox and DOH Policy Analyst Anna Kelsey.

Kathleen provided historical context of clinical trials. She shared examples of clinical trials conducted in African Americans (e.g., experiments conducted by James Marion Sims, the “Mississippi appendectomy,” the Syphilis Study, and studies that used Henrietta Lacks’ cells), noted the harms caused by those trials/experiments, and highlighted racial and ethnic disparities in HIV/AIDS (e) and inequality in HIV/AIDS treatment. Kathleen noted that all those studies/experiments and inequality in treatment have led to distrust.

Other meeting attendees shared via the Chat additional information on racial and ethnic disparities in HIV/AIDS and clinical trials:

- HIV/AIDS and Native Hawaiians/Other Pacific Islanders:  
<https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=81>
- HIV/AIDS and Asians: “Asians comprise 6 percent of the U.S. population and accounted for 2 percent of all new HIV infections in 2018. At the end of 2018, 17,600 of the estimated 1.2 million people with HIV in the United States and dependent areas were Asian<sup>1</sup>, and 1,100 were Native Hawaiians and Other Pacific Islanders (NHOPI).”
- People with Disabilities in Human Subjects Research: A History of Exploitation, a Problem of Exclusion: [https://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=3492078](https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3492078)
- Paradigm Shifts in Disability and Health: Toward More Ethical Public Health Research: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3828957/>

### Presentation on 2SHB 1745

Anna shared the following information regarding 2SHB 1745 and briefly explained what clinical trials are. For full bill 2SHB 1745, visit <https://lawfilesexext.leg.wa.gov/biennium/2023-24/Pdf/Bills/Session%20Laws/House/1745-S2.SL.pdf?q=20230531154848> (Section 6 on page 5 outlines the role of DOH in developing a report to the legislature).

- Purpose of 2SHB 1745: To increase participation and representation of diverse demographic groups in clinical trials of drugs, vaccines, and medical devices.
- DOH’s role: To produce a legislative report identifying underrepresented demographic groups, barriers to participation, and approaches for improving diversity in clinical trials
- Clinical trials:
  - Research studies to evaluate the safety and effectiveness of drugs and medical devices
  - Focus on treating specific conditions or specific populations
  - Can be studies for new drugs or for new uses of existing drugs
  - Clinical trial participants are volunteers who meet eligibility criteria
  - Eligibility criteria can include age, sex, treatment history, etc.



- Diversity in clinical trials:
  - Historically and currently, clinical trials have not been demographically diverse
    - For more information about Washington state history, visit <https://www.historylink.org>
  - Diversity in clinical trials is important because factors like race, ethnicity, age, and sex can impact how people react to medical treatment
  - Certain racial demographic groups are underrepresented in clinical trials, even when they are at higher risk of certain medical diseases
    - Example: American Indians/Alaska Natives make up 2% of the US population but only represent 1% of clinical trials despite experiencing health disparities and higher risk for certain health conditions
- Key elements of the 2SHB 1745 report
  - To identify
    - Underrepresented communities and demographic groups by race, sex, sexual orientation, socioeconomic status, age, and geographic location
    - Barriers to participation in clinical trials for underrepresented demographic groups
    - How clinical trial researchers can partner with community-based organizations to increase representation
  - To develop recommendations to
    - Increase diversity in clinical trials
    - Reduce barriers for participants in clinical trials
- DOH's approach: Engaging the Community Collaborative and Thought Partners
  - Working with Thought Partners to plan engagement with the larger Community Collaborative
  - Today: breakout sessions to begin exploring this topic
  - The DOH team intends to have follow-up engagement in September, if capacity permits.
    - Anna clarified that the engagement cannot and is not intended to definitively answer the questions posed by the report, and that the report does not ask all the questions related to this work. She explained that today's discussion is a starting point, and the answers that meeting attendees provide will not be used to create easy or definitive "fixes" to what is a large, structural problem.

## Q&A

An attendee asked if the report would address access to drugs that have been approved. Anna explained that DOH would answer the questions posed in the report, which is mandated by legislature, and would also point out that more needs to be done.

Todd and Cyril added that the Community Collaborative will continue discussions on those topics.



## Breakout Room Discussions

Meeting attendees were divided into three breakout rooms for discussion. Discussions in the three breakout rooms are summarized below.

**Questions 1:** *How can community-based organizations (CBOs) partner with clinical research organizations to recruit more diverse clinical trial research participants?*

Meeting attendees' collective input:

- Recruiting is challenging because of historical harms and distrust
- To improve participation, multiple iterations of work are needed, beginning with building trust
  - One way to overcome distrust is to include a knowledgeable community member as a part of the team that designs research studies
- Developing ongoing relationships between research institutes and community organizations is critical
  - Researchers/research institutes need to be actively engaged with communities
  - Communities need to know that researchers/research institutes are not just taking advantage of them as what was done historically
    - Researchers/research institutes should share information across a variety of platforms and in various formats and provide opportunities for open-ended feedback
  - Researchers should connect with CBOs serving the populations of focus to let them know about their intended research
    - Additionally, consider geography and reach out to rural areas in Washington state and other non-dominant locations, and develop a concentrated effort to inform marginalized communities of the rationale and importance of participating in clinical trials
  - Researchers should also understand and incorporate intersectionality's (e.g., race and HIV), and reach out to CBOs that 1) have the knowledge about where researchers should go and 2) can help with planning
  - Researchers/research institutes' outreach to communities should not be a one-time effort but rather a long-term commitment with a focus on relationship-building
  - Researchers need to build a true relationship with communities and understand the challenges that communities face
    - Understand that what works for one community may not work as well for another
- Research should not be just for the research institution but should benefit communities as well
- Research principals need to be rooted in diversity, equity, inclusion, and accessibility that do not cause harm



- Community-based participatory research should begin with the end in mind and consider CBOs as stakeholders
- Language accessibility and cultural connection to communities are important
- Having a trusted messenger would make acceptance easier; the trusted messenger could also be the interviewer
- Providing financial incentives and reducing the number of hoops are important; however, caution should be taken so that participants are not exploited
- Agencies need to reach out/show up in communities in need and build ongoing relationships

**Question 2:** *How can researchers better engage with BIPOC communities in Washington state to build trust and understanding around the importance of clinical trial participation?*

Meeting attendees' collective input:

- Being available and holding townhall meetings to answer community questions
- Including a knowledgeable community member as a part of the team that designs and/or conducts research studies
- Public health staff need to care for their communities
- Information/data sharing and transparency are important

**Question 3:** *In your experience, what role can community leaders play in promoting awareness and education about clinical trials within the BIPOC community?*

*(This question was discussed in only one breakout room. The question was brought up in another breakout room, but no one provided input at the time. The third breakout room did not have time to discuss this question.)*

Meeting attendees' input:

- Building trust and partnerships between community leaders can help create bonds between communities they serve
- Community leaders can help build partnerships and share experiences/information with others
- Community leaders tend to be the first ones to push back, ask difficult questions on behalf of their communities, and help create trust and answer questions
- Meeting attendees emphasized that it is important for DOH to create a space like the Community Collaborative so that community leaders and grantees can meet and develop partnerships

For comments, recommendations, or considerations regarding 2SHB 1745, please contact DOH Policy Analyst Anna Kelsey at [anna.kelsey@doh.wa.gov](mailto:anna.kelsey@doh.wa.gov) or 360-628-7483.

## **Next Steps and Contact Information**



Todd thanked session participants and noted that the Community Collaborative plans to continue the conversation on diversity in clinical trials in future sessions.

For more question, comments, or considerations, please contact Community Collaborative:

- Juliet Kwakye, Health Equity Communications Outreach Coordinator  
at [Juliet.Kwakye@doh.wa.gov](mailto:Juliet.Kwakye@doh.wa.gov)
- Frances Limtiaco, Community Investments and Engagement Manager  
at [Frances.Limtiaco@doh.wa.gov](mailto:Frances.Limtiaco@doh.wa.gov)

For calendar and more information on the Community Collaborative, visit  
<https://waportal.org/partners/home/community-collaborative/calendars>

For comments, recommendations, or considerations regarding 2SHB 1745, please contact DOH Policy Analyst Anna Kelsey at [anna.kelsey@doh.wa.gov](mailto:anna.kelsey@doh.wa.gov) or 360-628-7483.

For those who are interested in attending the webinar on August 28, 2023 regarding DOH's Legislative and Budget Priorities, please contact Joel Jordan at [joel.jordan@doh.wa.gov](mailto:joel.jordan@doh.wa.gov).