

AGENDA

PUBLIC HEALTH ADVISORY BOARD Strategic Data Plan Subcommittee

**April 18, 2023
1:00 - 2:00 PM**

Join ZoomGov Meeting

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Meeting ID: 160 542 1162

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Subcommittee members: Jackie Leung, Hongcheng Zhao, Rosemarie Hemmings, Veronica Irvin, Kelle Little, Jawad Khan, Dean Sidelinger, Marie Boman Davis

OHA staff: Victoria Demchak, Virginia Luka, Cara Biddlecom, Rose Harding.

1:00 – 1:15pm	Welcome and Introductions <ul style="list-style-type: none">• Welcome members• Approve March meeting minutes	Virginia
1:15- 1:25 pm	Draft outline discussion <ul style="list-style-type: none">• Inviting feedback on our draft outline regarding content, direction, and tone.	Victoria, Rose
1:25 – 1:50	Priority-setting follow-up <ul style="list-style-type: none">• Updated framework• OHA needs to review proposed recommendations more closely to scope time/ engagement.	Victoria, Dean
1:50 – 2:00	Public comment	
2:00	Adjourn	

MINUTES

PUBLIC HEALTH ADVISORY BOARD Strategic Data Plan Subcommittee

March 21, 2023

1:00 - 2:00 PM

Subcommittee members: Hongcheng Zhao, Dr. Rosemarie Hemmings, Veronica Irvin, Kelle Little, Jawad Khan, Dean Sidelinger, Marie Boman-Davis

Subcommittee members excused: Kelle Little

OHA staff: Victoria Demchak, Virginia Luka, Rose Harding, Cara Biddlecom

Welcome and Introductions

Subcommittee members and staff introduced themselves.

Jawad moved to approve the February subcommittee minutes and Veronica seconded. The subcommittee voted to approve the February 2023 meeting minutes.

Values related to public health data modernization

Rose introduced the PHAB handout called “Defining Values and Working Definitions for Strategic Data Plan Discussion”.

Rose asked the subcommittee to focus on defining values for:

- Data justice
- Data equity
- Community engagement and community roles in data creation and interpretation

Cara shared that values and principles will be able to be applied to priorities and resources that are needed to modernize public health data. The work ahead will be long and values and principles will guide what the subcommittee helps OHA to prioritize over time.

Hongcheng reflected on the principles in the document and how powerful they are.

Rose shared where the definitions came from through consultation between the Coalition of Communities of Color and the OHA Equity and Inclusion Division. Other definitions are from the book *Data Feminism*.

Dr. Hemmings reflected on a prior discussion about how “community” is defined and asked if the group had agreed on a definition for “community”. Dr. Hemmings also brought forward Meaningful Use for Health IT and the need to allow community to define needs for the purpose of data collection.

Rose responded in summary that public health needs to center data collection around what communities want to know and would find useful.

Jawad reflected that related to community engagement – is there already a sense of what perspectives public health does collect already?

Cara shared that there is lesser direct involvement by communities in data collection and this is an opportunity for public health as a whole to receive direction from PHAB.

Veronica added that OHA has done a good job in partnering with communities related to the State Health Improvement Plan, and this could be a starting place.

Cara asked the subcommittee if they had other thoughts on a community engagement value for public health data. Jawad asked, “How can public health leaders actively involve and engage with marginalized communities in the data analysis and storytelling process? What specific strategies can be used to ensure that these communities feel heard and that their perspectives are valued? What steps can PHAB take to overcome the challenges and biases that can arise in data science methods and processes? How can we ensure that data science methods are used in a way that is inclusive, pluralistic, and values multiple perspectives and voices, particularly those of marginalized communities?”

Dean reflected that Jawad’s comments focus on each step of the process and improving over time – data collection, data analysis and reporting were all reflected in Jawad’s critical questions.

Jawad raised that community-based participatory research summarizes exactly what we are trying to accomplish related to community engagement in data and can be a tool for achieving our vision. <https://www.nimhd.nih.gov/programs/extramural/community-based-participatory.html>

Hongcheng reflected on his work in a community-based organization and the importance of community-specific data.

Rose reviewed the data justice definition and value, with the link going to comprehensive and actionable items.

Dr. Hemmings affirmed the data justice summary and its alignment with the work being discussed.

Rose encouraged the subcommittee to share feedback ongoing as other thoughts come to mind between meetings. Rose reviewed the data equity definition and value.

Dr. Hemmings asked whose responsibility it is to take the values and definition and operationalize it? Who takes the values and definitions and operationalizes them with data collection, use and analysis? Dr. Hemmings said this document should be a living document.

Public comment

No members of the public commented.

Meeting adjourned at 2:01 pm.

PHAB Strategic Data Plan Recommendation Outline

1. Introduction

2. Acknowledgments

3. Background

The Public Health Division of the Oregon Health Authority has been investigating the usefulness, accessibility and validity of its data to represent the state's rapidly changing population. This is consistent with Public Health Modernization, a model of public health alignment and investments to improve the public health system across Oregon's public health partners. These efforts were implemented in 2015 with legislative authority for public health modernization and the advent of the Public Health Advisory Board (PHAB) to advise and direct strategic changes.

This work to better identify and represent Oregonians has not been isolated to public health. Other initiatives across the Oregon Health Authority and the Oregon Department of Human Services have increased disaggregated data collection on race, ethnicity, language and disability; on sexual orientation and gender identity; and screenings on housing instability and food insecurity have spread across health and human services settings. Overall, investments in data quality and collection have been widespread and have had two areas of focus: improving disaggregated demographic data on community and developing categories that better define individuals as they define themselves.

This document is designed to be a living document, where the Public Health Advisory Board will provide updates on assumptions and priorities as this work proceeds. The PHAB plans to review this set of recommended actions on a [biannual?] basis. This field of work is new to the Public Health Division and thus is starting in a space of questions. As staff and Board members learn more, this document will become more specific and responsive to community member and the PHAB's needs.

4. Values for modern public health data

In reviewing work from across the Public Health Division and the expertise this subcommittee brings from across Oregon, the following values have been determined to be central. The Strategic Data Plan Subcommittee has advised the group that to achieve the primary goal of data justice, the Public Health Division must invest in community engagement and practices

that promote data equity. The definitions that we are starting with to direct our attention are below.

Data Justice:

“Data justice recognizes that the types of data the government collects and relies on are insufficient for understanding community needs, experiences and, equally important, desires. These data do not represent communities in ways that communities would represent themselves – and government data often entirely erases some communities due to “the problem” of small sample size (e.g., Pacific Islanders) or using too broad, and ultimately meaningless, categories (e.g., Asian).” - [Coalition of Communities of Color, in consultation with OHA’s REALD & SOGI Team](#)

Data Equity:

To achieve equitable data representation for diverse communities, we must work to dismantle historic and ongoing systems of oppression in data science. Communities must be engaged at all levels of planning, implementation, and evaluation of data systems and power must be shared through transparency and accountability measures whenever possible.

Community Engagement:

Community engagement in data science is a pluralistic approach that seeks out and values diverse perspectives in all phases of data processes. To prevent the suppression of community voices in data, we must find more ways to uplift community perspectives in our methods without constraining them for the sake of long-standing and outdated misconceptions of clarity and control. Embracing pluralism in data science means we strive to adopt and diffuse diverse methods for the collection, analysis, and dissemination of public health data.

5. The context of this work and recommendations on the state level

- Framing: Where are we today and where do we need to move? -> Identify available change frameworks
- Framing: Dependencies on other public health systems partners -> Authority for change
- Staff and committee identify framework to operationalize these recommendations that align with the change frameworks and authority.

6. Recommended Activities

[Describe intent and timeframes anticipated]

Recommended short-term activities for state public health

These are divided by area of work and a range of recommended activities from this committee’s discussion and the collaborative work between the Public Health Division and community-based organizations.

Data equity	
1. Accessible data that’s community or culturally specific. Data should be sortable, as far as possible, by REALD, SOGI, geography and faith-based proxies.	<ul style="list-style-type: none"> - BRFSS data - Provide navigable BH and MH data, including indicators and geographically specific work - Youth health - Sortable by <ul style="list-style-type: none"> o REALD, cultural communities o SOGI o Geography o Faith-based proxies? - Transparency and communication on the data collected and published, including its limitations, how data is used, collected, analyzed, and its presentation and context. - Develop online and other tools that help data users navigate data systems and develop data requests.
2. Develop working definitions of “actionable data” to direct community engagement	<ul style="list-style-type: none"> - Identify partners and convene discussions to understand data priorities/ needs, then share actionable data at appropriate levels (Tribal, cultural community, geographic, etc.)
3. Develop toolkits for data work at all levels of use	<ul style="list-style-type: none"> - Develop a toolkit of best practices for governmental public health to support access to data, analysis, and framing, including being critical of dominant ways of working with data, questioning existing assumptions, questioning objectivity, incorporating qualitative data, and assuming that data does not communicate for itself. - Develop a parallel toolkit for community-based organizations and community researchers. - In both, incorporate data limitations: representation, methods, who is excluded and demographic definitions. Incorporate how context and qualitative data can add nuance. - Demonstrate how is presently used with the public, including in state and community health assessments.
Data Justice	
4. Data rights and governance	<ul style="list-style-type: none"> - Describe governance for data quality, visualization, technology, etc. - Develop community governance model for how data are collected, used, reported and how governance should be conducted
5. Elevate community-identified issues	<ul style="list-style-type: none"> - Work to leverage existing resources that address the health needs raised in this work.
Community Engagement	

6. Develop a framework to incorporate community-developed data	- Crosswalk community-identified community health factors to state public health plans.
7. Ongoing engagement	- Invite community feedback regarding the data modernization assessment and inventory. - Proxies for culturally or religiously based communities?

Long term recommendations

These were identified as longer-term recommendations because they may require additional investments, multi-year investments, or conversations with state and national organizations that define or receive this data.

Data Equity	
1. Invest in different data collection strategies, including Census-style methods	- Engage and defer to community-based organizations and /or regional health equity coalitions in survey administration, including Tribal and Native American organizations
2. Identify different paradigms of data collection and advocate for future data efforts.	- Investigate county health rankings and BIPOC data hubs as possible conceptual frameworks for data collection - Conduct a minimal BRFSS – explore lessons from the CA Health Interview Survey (CHIS) - Continue long-term sustained, compensated community-led data collection - Call upon OHA as a grant recipient to advocate for changes in the national framework for BRFSS and other national health survey administration to achieve greater flexibility from federal requirements. - Develop possibilities for changes in data practices from federal funders to alter the BRFSS questions and/or methods to respond to community needs.
3. Improve survey translations	- Establish a survey translation advisory committee
4. Improve communication on survey activities	- Demonstrate transparency in how BRFSS and OHT data is used by OHA and by others
5. Add community-responsive questions to existing surveys	- Incorporate non-western questions about health and health care in surveys - Include questions on protective factors, particularly involvement in tribal and community activities.
Data Justice	
6. Data sovereignty and governance	- Protect tribal data and sovereignty with data access requirements, tracking posting and publishing of data

	<p>analyses and reports, ensure transparency and oversight by tribal and AI/AN communities.</p> <ul style="list-style-type: none"> - Have the Oregon Health Authority’s Public Health Division and Pacific Islander leaders enter a project evaluation period to assess the effectiveness of the community-led research model, including Data Sovereignty Agreement and design the next phase of this critical body of work. - Support ongoing community governance model for data collection, use, and reporting.
7. Data collection oversight	<ul style="list-style-type: none"> - Continue data project teams and ensure team members are made up of folks who share experiences of those being “researched.” Let those teams shape the next steps of survey modernization work - Build in time and resources necessary for relationship development between governmental public health and community partners in data - Integrate community leadership in survey development, administration, analysis and use - Re-engage the health equity researchers of Oregon (HERO) group
Community engagement	
8. Workforce and data engagement	<ul style="list-style-type: none"> - Invest in community-based organizations and governmental public health to increase capacity for data engagement, analysis and collection. - Build a stronger workforce within existing organizations - Build a workforce that represents the communities who are most impacted by this work by celebrating and uplifting the knowledge in community.

9. Conclusion and commitments [to be updated biannually]

This should include concrete recommendations to operationalize these values, or direct PHD to do so:

- Consider whether OHA should be engaging in or investing more time/ resources in community participatory research, qualitative research, or community engagement toward these ends.

Include a suggestion to ensure that the document is a living document

- Identify periodic process measures for accountability on activities and progress, invite PHAB to periodically review these recommendations and values.
- Consider incorporating these and other recommendations for other PHAB activities
- Request ongoing updates from PHD