AGENDA

PUBLIC HEALTH ADVISORY BOARD
Strategic Data Plan Subcommittee

October 31, 2023
1:00 - 2:00 PM

Join ZoomGov Meeting
https://www.zoomgov.com/j/1605421162?pwd=Y24rL0hJUmFGV1hzdjNjSVJFZzNmZz09
Meeting ID: 160 542 1162
Dial by your location
      +1 669 254 5252 US (San Jose)
Subcommittee members: Jackie Leung, Hongcheng Zhao, Rosemarie Hemmings, Veronica Irvin, Kelle Little, Jawad Khan, Dean Sidelinger, Marie Boman Davis

OHA staff: Victoria Demchak and Rose Harding

Time	Item	Lead
1:00 – 1:15pm	**Welcome and Introductions** • Welcome members • Approve August meeting minutes	Victoria
1:15 – 1:45 pm	**Introduce revised SDP recommendation document: summary of changes** • Incorporated comments from previous meeting • Other changes, final concerns? • Optional review: slides	Victoria, Dr. Sidelinger
1:45 – 1:50 pm	**Upcoming meetings and ongoing work** • Joint meeting with Accountability metrics subcommittee on Friday, November 3 • Presenting our final work to PHAB on November 9 for approval	All
1:50 – 2:00 pm	**Public comment**	

2:00   **Adjourn**

PUBLIC HEALTH ADVISORY BOARD

Strategic Data Plan Subcommittee

August 15, 2023
1:00 PM – 2:00 PM

Participants: Hongcheng Zhao, Dean Sidelinger, Veronica Irvin, Jawad Khan, Kelle Little, Marie Bowman-Davis, Jackie Leung
Staff: Victoria Demchak, Rose Harding

Welcome and Introductions

- PHAB subcommittee members and OHA staff introduced themselves.
- It was noted that there were several members of the public in attendance, as were some members from LPHAs.
- Jawad moved to approve the meeting minutes for the June 20th meeting; Marie seconded this motion.

Discussion on the status of the document

- Marie brought up that that in the Background section of the document that PHAB shows up twice. She proposed changing some acronyms to avoid redundancy. She suggested biannual reviews in the end and asked members to consider a biennial update. She also notes that the phrase "data science" is used in multiple sections of the documents and recommends that we provide a definition or reference for what we mean by that phrase.
- Dean said that he is committed to bring back this document to this workgroup if there are any major changes before the two-year period.
- Veronica said that she likes adding context and the reorganization of the document.
- A question was asked about whether one of the sections of the document would encompass supporting data sovereignty and governance.
  - Discussed how the long-term goals are to develop data sovereignty agreements with Tribal data and PI data because those communities have sought it.
- A question was asked about whether there are other communities that data representation would expand to or that tribal and PI data would be the only ones that the document would be working with.

- A suggestion to adding broader language reflecting existing work and adding broader language to reflect what might need to be figured out was made.

- A suggestion to adding some more language on page 6 regarding faith-based proxies was made.
- Hongcheng noted that checking of BRFSS spelling throughout was important.

Discussion on what do we do with the PHAB

- Marie remarked that a timeline, the number of meetings, what the workgroup has done, and when the work started are all things needed to reflect upon when meeting with PHAB. She also notes providing context for why this is being presented will help members understand the reasoning for their support.
- Dean commented that a foundational document on the next steps for language and direction, for survey data from ELC and steps in investing dollars to work on broader systems development would be beneficial. He also noted that he wants to share this with the broader public health system. He said that this would help develop goal posts/ metrics on reporting back to the broader PHAB and represent how we're utilizing metrics to pinpoint where the work group is running into trouble.
- It was noted that a big part of this process is how PHAB will resources these efforts and develop tools for accountability.
- Incorporation of these topics into the presentation for the broader PHAB meeting would help everyone understand the scope of the project. Bringing additional documents about data modernization was also noted as being helpful.

- Dean stated that the purpose of these smaller documents was to help people understand the workgroup's direction. He also said that he did not want to have something too overwhelming but something more targeted and focused. He commented that he was welcome other ways to compile and share info on the workgroup's data approach.
- Veronica asked where these documents would be accessible.
- Dean answered by saying they would probably be on the PHAB website but also wants to have them in other places so it's findable.
- Marie stated that she would like to make the document explicit for the presentation to the PHAB, recommending that the workgroup makes it into a PowerPoint or some visual. She recommended have a shorter presentation and more time for discussion.
- Veronica agreed by nothing that the document is not a long document. She added that by having a shorter presentation, the workgroup could address funding concerns and the larger context in which this document would be used. She also added that they should include that they're planning to work with the accountability metrics subcommittee.
- Rose stated that this document should be brought to CLHO.

- Marie noted that if a document is shared with CLHO, that it should also be shared with PHAB for consistency.

Update to the next PHAB

- Marie said that she was up for sharing the presentation/work to the PHAB and that she wanted to work with Dean, Victoria, and Rose.

Public comment

- Sharon thanked the workgroup you for having her and that she looked forward to attending more of meetings.

Meeting Adjourned

Public Health Advisory Board
Recommendations for strategic data initiatives for the state
October 2023

These recommendations were developed by a subcommittee to the Oregon Public Health Division to provide strategic direction to the Public Health Division (PHD) and the Oregon Health Authority (OHA) to support changes in data systems, processes and methods to make data accessible, reflective and useful for community members.

Subcommittee Membership

Marie Boman-Davis, Washington County Health and Human Services	Jawad Khan, Muslim Education Trust
Veronica Irvin, Oregon State University	Marjorie G. Mcgee, OHA Equity and Inclusion Division
Dr. Rosemarie Hemmings, community member	
Jackie Leung, Micronesian Islander Community	Dean Sidelinger, OHA Public Health Division
Kelly Little, Coquille Indian Tribe	Hongcheng Zhao, Oregon Chinese Coalition

Purpose
This document identifies a set of practices for data collection, use and analysis and advocate for future public health data efforts within Oregon. While this is not exhaustive, these recommendations require Public Health Division to stay apprised of different methodologies and technologies with potential to be used for misinformation, mischaracterization and bias, including artificial intelligence.

Acknowledgements
Partners with the survey modernization process were foundational in developing these recommendations and determining next steps for the Public Health Division. Their work products with the Public Health Division are linked below and we appreciate their wisdom and commitment to this work.

Background
The Public Health Division of the Oregon Health Authority has been reviewing the usefulness, accessibility and validity of its data to represent Oregon's rapidly changing population. This is consistent with Public Health Modernization, the 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 change.

In 2019, Program Design and Evaluation Services (PDES), an intergency research and evaluation unit with the OHA Public Health Director's Office, launched culturally specific project teams with community members, leaders, researchers, and organizations to modernize the ways we collect, analyze, and report population health data in Oregon. The overall goals of the project include addressing the roots of inequality in data collection, providing a community-centered critique of survey design and purpose, and developing actionable recommendations for OHA for engaging with communities from design, analysis, and reporting data. This project started with consolidating and reviewing racial data from two large statewide surveys: the Behavioral Risk Factor Surveillance Survey (BRFSS) and the Student Health Survey (SHS).

Lead Organization	Communities	Project Goals	Link to Report
Coalition for Communities of Color (CCC)	African American African Immigrant and Refugee Latinx	• Review existing data • Conduct participatory analysis • Communities design additional data collection	Engaging Communities in the Modernization of a Public Health Survey System
Northwest Portland Area Indian Health Board (NPAIHB)	American Indian Alaska Natives	• Review existing data • Conduct participatory analysis • Collect additional data to provide context, but in this case, the team uses Tribal BRFSS data.	Oregon Tribal Survey Modernization Project
Oregon Pacific Islander Coalition (OPIC)	Pacific Islander	• Establish community centered methodology to collect original data	This is the Way We Rise: Pacific Islander Data Modernization in Oregon

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 (PHAB) will provide updates on assumptions and priorities as this work proceeds. This subcommittee recommends that the PHAB 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 the needs of community members and the PHAB.

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:
- Data justice
- Data equity
- Community engagement

The Strategic Data Plan Subcommittee has advised the PHAB that to achieve the primary goal of data justice, the Public Health Division must invest in community engagement and practices that promote data equity.

Recommended Activities
These activities have been recommended by the committee's discussion and generally build on the collaborative work between the Public Health Division and community-based organizations. The timeframe for the work reflects the degree of resources required: long-term require a significant separate funding, staffing or time to develop alternative methodologies, such as with the CDC

These recommendations are sorted by the primary domain of the work: data equity, data justice or community engagement. Each domain includes a working definition that the committee developed, the context for that definition, and a set of strategic recommendations and activities that would advance PHD's work in this domain. Recommendations and activities were sourced from the committee and from prior feedback and conversations with community partners and Tribal governments.

I.   Data justice

Definition: "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

Context
Data justice must be a central value as OHA works to advance data equity for all Oregonians. OHA and communities must work together to define a new data governance model that divests from data practices that have harmed historically marginalized communities, empowers

community leadership in how data are used and stories are told, and ultimately better serve all Oregon communities. Data justice requires OHA to build trust with all Oregon communities so that deep, lasting community engagement can serve as the foundation for decision-making that is both reflective of all Oregonians and creates formal pathways for communities to elevate issues to OHA leadership.

A good example of this work is OHA's partnership with Pacific Islander communities to produce and share the PI Heal project, a Pacific Islander data modernization project that was community led, researched, and reported. Lessons learned from that project can be used to develop community engagement and governance models and generalize data justice centered practices.

Short Term Data Justice Goals	Activities
1. Define and commit to data rights and governance	• Describe governance for data quality, visualization, technology, and other methods that make data usable. • Develop community governance model for how data are collected, used, reported and how governance should be conducted
2. Elevate community-identified issues	• Work to leverage existing resources that address the health needs raised in this work.
Long Term Data Justice Goals	Activities
3. Support data sovereignty and governance	• Protect Tribal data and sovereignty with data access requirements, tracking posting and publishing of data analyses and reports, ensure transparency and oversight by Tribal and native communities. • 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.

II. Data equity

Definition: 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. Moreover, promoting data equity requires the recognition and rectification of historical biases and data gaps that disproportionately affect marginalized communities. Efforts should be made to collect and analyze data that accurately reflects the lived experiences, challenges, and aspirations of diverse populations. By actively addressing data gaps and improving data

collection methods, we can ensure that decision-making processes are based on comprehensive and representative information, reducing the perpetuation of systemic biases[1].

Context

Data equity is a set of practices that are necessary to achieving data justice. These range from access to data representing specific communities and sharing information for other organizations to better understanding the data desires for specific communities. As the producer and collector of data, it falls to the Public Health Division to develop tools and resources that increase the ability for partner organizations to access and use the data. Without these steps, it is difficult for data and organizational partners to understand, analyze and use the data collected on Oregon residents.

Short Term Data Equity Goals	Activities

1. Provide accessible data that's community or culturally specific. Data should be sortable, as far as possible, by race, ethnicity, disability, language, sexual orientation, gender identity, geography, and proxies for faith and other statuses/ experiences.	• Large-scale public health data, such as behavioral risk factor surveillance system (BRFSS) data
	• Provide navigable behavioral and mental health data, including indicators and geographically specific work
	• Youth health
	• Disaggregated by
	    o Race, ethnicity, language, disability and cultural communities
	    o Sexual orientation and gender identity
	    o Geography
	• Research available methods to gather data on faith-based communities and others that are not clearly identified through existing data categories.
	• 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	• Identify partners and convene discussions to understand data priorities/ needs, then share actionable data at appropriate levels (Tribal, cultural community, geographic, etc.)
Long Term Data Equity Goals	Activities
3. Develop toolkits for data work at all levels of use	• 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,

Commented [K(1): As a side - possible new census R/E categories How Race Categories on U.S. Census Forms Have Evolved - The New York Times (nytimes.com)

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[1] This working definition draws heavily from "Data Feminism", Catherine D'Ignazio and Lauren F. Klein. Cambridge, MA and London, England: the MIT Press, 2020.

		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.
4.	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
5.	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.
6.	Improve survey translations	• Establish a survey translation advisory committee
7.	Improve communication on survey activities	• Demonstrate transparency in how BRFSS and OHT data is used by OHA and by others
8.	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.
9.	Develop data collection oversight	• 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

III.   Community engagement

Definition:
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.

Context
Based on lessons learned through our survey modernization projects and feedback from community members, leaders, researchers, and organizations, we must invest in community engagement. We need to be willing to share power and invite our community partners to participate in processes that guide our work. We must fund community partners directly and sufficiently for their time and expertise including adult and youth partners. We should provide transparent and flexible budgets and timelines to allow sufficient time and resources for relationship building and avoid overburdening community partners.

Short Term Community Engagement Goals	Activities
1. Develop a framework to incorporate community-developed data	• Crosswalk community-identified community health factors to state public health plans.
2. Provide ongoing engagement	• Invite community feedback regarding the data modernization assessment and inventory.
Long Term Community Engagement Goals	**Activities**
3. Support workforce and data engagement	• Enhance investments in community-based organizations and governmental public health to increase capacity for data engagement, analysis and collection. • Strengthen the 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.

Conclusion and biannual commitments

This committee recommends the following practices to check on progress and operationalize these values. These practices should be taken as an accountability practice for the Public Health Division and should be performed at least biannually.

The commitments from 2023 for 2025 are:

- Review whether OHA should be engaging in or investing more time/ resources in community participatory research, qualitative research, or community engagement toward these ends.
- Review existing and develop additional opportunities for collaboration with statewide and regional data collection and analysis systems, including health care.
- Request staff to include process measures for accountability on activities and progress during the next review.
- Review updates on these and aligned projects from the Public Health Division.

Public Health Advisory Board
Strategic Data Plan Subcommittee Recommendations

The Strategic Data Plan subcommittee reviewed work from across the Public Health Division and brought its own expertise from across Oregon to recommend values and activities. This subcommittee is advising the Public Health Advisory Board that to achieve the primary goal of data justice, the Division must invest in community engagement and practices that promote data equity.

Values

- 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…"

- Data equity

    "Efforts should be made to collect and analyze data that accurately reflects the lived experiences, challenges, and aspirations of diverse populations…"

- Community engagement

    "… a pluralistic approach that seeks out and values diverse perspectives in all phases of data processes…"

Recommendations

Data justice	Data equity	Community engagement
- Community/culturally specific accessible data. - Develop working definitions of "actionable data" - Develop toolkits for data work at all levels of use - Invest in different data collection strategies - Improve survey translations Improve communication on survey activities - Add community-responsive questions to existing surveys	- Data rights and governance - Elevate community-identified issues - Data sovereignty and governance - Data collection oversight	- Develop a framework to incorporate community-developed data - Ongoing engagement - Develop a workforce that supports data engagement within OHA and with community-based organizations

Strategic Data Plan Subcommittee members

Marie Boman-Davis, Washington County Health and Human Services

Dr. Rosemarie Hemmings, community member

Veronica Irvin, Oregon State University

Jackie Leung, Micronesian Islander Community

Kelly Little, Coquille Indian Tribe

Jawad Khan, Muslim Educational Trust

Marjorie G. Mcgee (she/her), OHA Equity and Inclusion Division

Dean Sidelinger, OHA Public Health Division

Hongcheng Zhao, Oregon Chinese Coalition

PHAB Strategic Data Plan Review
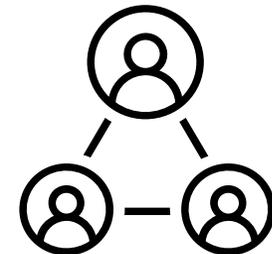
{Presenters}

Strategic Data Plan Values

Data justice

Data equity

Community engagement

Process

- Reviewed Survey Modernization reports and recommendations; added the Strategic Data Plan members' recommendations

- Reviewed Behavioral Risk Factor Surveillance System (BRFSS) and other data improvement initiatives within state public health

- Developed and workshopped values for data equity initiatives.

Timeline

2021: Committee convened to develop recommendations on a governmental PH strategic data plan

2022: Committee receives guidance from community specific survey modernization reports and presentation

2023: Develops set of definitions and recommendations.

Deliverables

Values to guide data justice and equity initiatives

Developed and revised charter

Set of strategies and activities to improve public health data

Recommendation and guidance for review of data activities on a biennial basis

Values

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…"

Data equity

- "Efforts should be made to collect and analyze data that accurately reflects the lived experiences, challenges, and aspirations of diverse populations…"

Community engagement

- "… a pluralistic approach that seeks out and values diverse perspectives in all phases of data processes…"

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 justice goals

1. Define and commit to data rights and governance

2. Elevate community-identified issues

3. Support data sovereignty and governance

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. Moreover, promoting data equity requires the recognition and rectification of historical biases and data gaps that disproportionately affect marginalized communities.
- Efforts should be made to collect and analyze data that accurately reflects the lived experiences, challenges, and aspirations of diverse populations.
- By actively addressing data gaps and improving data collection methods, we can ensure that decision-making processes are based on comprehensive and representative information, reducing the perpetuation of systemic biases.

This working definition draws heavily from "Data Feminism", Catherine D'Ignazio and Lauren F. Klein. Cambridge, MA and London, England: the MIT Press, 2020.

Data equity goals

1. Provide accessible data that's community or culturally specific. Data should be sortable, as far as possible, by race, ethnicity, disability, language, sexual orientation, gender identity, geography, and proxies for faith and other statuses/experiences

2. Develop working definitions of "actionable data" to direct community engagement

3. Develop toolkits for data work at all levels of use

4. Invest in different data collection strategies, including Census-style methods

5. Identify different paradigms of data collection and advocate for future data efforts.

6. Improve survey translations

7. Improve communication on survey activities

8. Add community responsive questions to existing surveys

9. Develop oversight methods for data collection

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.

Community engagement goals

1. Develop a framework to incorporate community-developed data

2. Perform ongoing engagement with community members

3. Support workforce and data engagement

Discussion