Public Health Advisory Board
Strategic Data Plan

Recommendations for strategic data initiatives for state public health
Approved November 9, 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, Conference of Local Health Officials and Public Health Advisory Board (PHAB)
- Dr. Rosemarie Hemmings, community member
- Veronica Irvin, PHAB Chair
- Jackie Leung, Micronesian Islander Community and PHAB member
- Kelle Little, Coquille Indian Tribe and PHAB member
- Jawad Khan, Muslim Education Trust and PHAB member
- Marjorie G. McGee, OHA Equity and Inclusion Division
- Dean Sidelinger, OHA Public Health Division
- 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. This builds on and should be used along with the PHAB health equity policies and procedures. 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 interagency 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 Agreements and design the next phase of this critical body of work. • Support ongoing community governance models 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
	   ○ Race, ethnicity, language, disability and cultural communities, existing or new categories since this is dynamic.
	   ○ Sexual orientation and gender identity
	   ○ 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.)

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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.

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, 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 to:
- 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.
- Ensure staff provide updates on these and aligned projects from the Public Health Division.