

AGENDA

PUBLIC HEALTH ADVISORY BOARD Strategic Data Plan Subcommittee

August 16, 2022

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

OHA staff: Victoria Demchak, Virginia Luka, Diane Leiva

1:00 – 1:15

Welcome and Introductions

- Welcome members and staff
- Approve June and July meeting minutes (#2 and 3)
- Recording of May 2021 PHAB meeting presentation with survey modernization partners: <https://youtu.be/LEQN7kCy7rk>

Victoria Demchak
and Virginia Luka,
Oregon Health
Authority

1:15 – 1:50

Strategic Data Plan subcommittee purpose

- Why now? Changes in public health data (Survey modernization overview document, #3)
- Review draft subcommittee charter (#4)
- Supportive content (optional discussion, if time permits)
 - Strategic data plan high-level outline (#5)
 - Community specific reports (#6)

All

1:50 – 2:00 **Public comment**

2:00 **Adjourn**

Draft Minutes

PUBLIC HEALTH ADVISORY BOARD Strategic Data Plan Subcommittee

**June 21, 2022
1:00 - 2:00 PM**

Subcommittee members: Kelle Little, Hongcheng Zhao, Rosemarie Hemmings, and Veronica Irvin,

OHA staff: Diane Leiva, Victoria Demchak, Virginia Luka.

Welcome and introductions

- **May meeting minutes approved**

Overview: Staff explained why subcommittee was created, what the committee is working toward.

Introduction of new staff:

Virginia – Program specialist for Pacific Islander community. Was asked to lead a Pacific Islander data collection project, that project launched Pacific Islander data modernization project with the state. Experience with data collection and data analysis through qualitative, decolonization framework to help with data justice, data sovereignty.

Data sovereignty happens on local level in developing data for us, by us and sharing with us. Multnomah County signed data sovereignty agreement with Pacific Islander coalition. Example of data collection that was not based off communities: information on COVID cases at the beginning of the pandemic wasn't separated by race/ethnicity. Once it was brought attention and it started to be separated by race/ethnicity it showed that the Pacific Islander community was the population with the highest rates of contracting the virus, highest rate of hospitalization, not getting vaccinations, etc. With this change – including race, disaggregated when possible – data could now assist the community.

Dr. Hemmings – Can relate with what was said by Virginia as it rings true with black communities and data, especially during the pandemic. Did raise concerns in the beginning of the data not showing race/ethnicity with OHA. Had a lot of back and forth with the importance of disaggregating the data between race/ethnicity. Was able to help OHA see the importance. One of the reasons I joined the strategic data plan committee to ensure the framework is representing people.

Kelle – Experience with data sovereignty with federal recognized tribes. As we all know that there is significant trauma in the Native American communities due to exploitation and unethical practices. Wanted to acknowledge that there is a difference as they are a sovereign government as well.

Hongcheng – involving CBOs brings the community to the table with data and helps public health and community. Data is hard to make sure it is including everything. We are heading towards the right direction to collect data that includes communities. Including communities ensures we get the data needed for communities/sub communities.

Discussion of document defining possible outcomes for strategic data planning, including new framework for collecting data.

Questions to discuss next meeting:

- Is there a charter or bylaws?
 - o Charter was created before COVID pandemic but now needs to be looked at to change.
- Do have a document that outlines what products this subcommittee should to create a framework.
 - o There is a modernization in action framework that helps clear up some questions of what we will be doing looking into. Diane to send out to committee members to review.

Meeting adjourned.

Draft Minutes

PUBLIC HEALTH ADVISORY BOARD Strategic Data Plan Subcommittee

July 19, 2022

1:00 – 1:10 PM

Subcommittee members: Rosemarie Hemmings and Dean Sidelinger.

OHA staff: Diane Leiva, Victoria Demchak, Virginia Luka, Cara Biddlecom

Committee opened.

- Two members joined, others had conflicts. Agenda postponed to August 16 meeting.

Meeting adjourned, 1:10 pm.

Brief Update on Survey Modernization

March 2022

Background

The Oregon Legislature's Modernization funding for the 2019-2021 biennium included funding to update the adult (BRFSS) and youth (OHT/SHS) survey systems to address these challenges and gather better data for specific communities. The Office of the State Public Health Director (OSPHD) directed Program Design and Evaluation Services (PDES)¹ to lead this project, and the Oregon Public Health Division (OPHD) Science and Epidemiology Council (SEC) provided scientific oversight.

The need and approach for modernizing Oregon's population wide surveys came in several ways including our previous work with communities in various projects, work with African American, Pacific Islander, Alaska Native and other communities, academics, and practice partners. Our approach was informed by the literature and over 30 key informant interviews with local community-based organizations.

The Behavioral Risk Factor Surveillance System (BRFSS) is a telephone survey to collect state-specific data from individual adults on preventive health practices and risk behaviors that are linked to chronic diseases, injuries, and preventable infectious diseases in the adult population. The BRFSS is partially funded by the Centers for Disease Control (CDC). Health departments are dependent on BRFSS data for a variety of purposes, such as targeting services, securing funding, and measuring progress toward public health objectives.

The BRFSS has problems of equity, data quality, and sustainability: (1) the BRFSS is increasingly not representative of all Oregonians, especially for BIPOC communities², (2) there are growing concerns about the validity of BRFSS data given the lack of context and sensitivity of many questions, and (3) the BRFSS is expensive to conduct -- BRFSS costs close to \$1 million annually and the last racial and ethnic oversample cost over \$500 per completed survey and was still not representative of certain major racial and ethnic groups (e.g., Pacific Islanders).

Oregon's Student Health Survey (SHS) is a collaborative effort with the Oregon Department of Education to improve the health and well-being of all Oregon students. The SHS is a comprehensive, school-based, anonymous, and voluntary health survey of 6th, 8th and 11th graders that provides key data for OPHD and ODE for program planning and policy efforts. Prior

¹ PDES is an interagency applied public health research and evaluation unit, within OPHD and Multnomah County Health Department, and currently coordinates the BRFSS and school-based youth surveys for OPHD.

² BRFSS implementation methods (random phone call) exclude communities who are generally mistrustful of government. BRFSS questions are often seen by communities as invasive and lacking the contextual questions to make them meaningful.

to 2020, student health data was collected through the Oregon Healthy Teens Survey, the Student Wellness Survey, and the Youth Risk Behavior Survey.

Survey Modernization Efforts: 2019-2021 Biennium

Rather than investing in an expensive and limited use racial oversample that would only update the content of the surveys, PDES decided to take an approach that examined the root design and implementation of the surveys. PDES invested in two complementary approaches: 1) piloting innovative statewide survey methods that incorporated the most recent scientific advances and (2) collaborating with Oregon tribes and BIPOC and communities to collect, analyze, and contextualize culturally specific survey data. Oregon is among one of the few states to engage communities in modernizing our public health data surveys. We are sharing this information about extensive collaboration with communities in the design of public health surveys to offer a model for how such collaborations can be valuable and feasible in public health systems.

The work included:

- 1) Collaborating with and funding the Coalition of Communities of Color and the Northwest Portland Area Indian Health Board to form and facilitate community-specific data project teams for the Latinx, Black/African American/African Immigrant & Refugee, and American Indian/Alaskan Native communities. Each team included 5-6 members including community researchers and leadership from community-based organizations (CBOs). They used community-identified priorities to guide the analysis, interpretation, and contextualization of BRFSS (4-year aggregate 2015-2018), and OHT (2019) data. Some partners also led community-driven data collection on topics and methods of their choice. Their critique and recommendations are summarized in two reports: [Engaging Communities in Public Health Survey Modernization](#) and [NPAIHB Survey Mod Report to OHA FINAL MARCH 2022](#).
- 1) Funding Pacific Islander researchers, community organizers, individuals, and CBOs to conduct community-led data collection and build capacity within Pacific Islander communities around research and data. The Pacific Islander community is particularly under-represented on statewide surveys. Using a community-led research model, a Pacific Islander core team of researchers worked with PDES and sought guidance from various advisory groups including the Oregon Pacific Islander Coalition. The Pacific Islander-led core team identified priorities for this project, co-designed the data collection methods that would work best with their communities, and developed a community health assessment tool. They analyzed both the qualitative and quantitative data using a participatory approach ([ref](#)) with a broader team of Community Research Workers. The core team co-wrote the final report, which includes results and recommendations in the report: [PI HEAL Report 2021](#).

Detailed results and recommendations can be found in each of the reports. Taken together, the overall results from these community collaborations and the statewide BRFSS pilot of innovative methods highlight that OPHD needs to revamp its community health data collection systems.

Ongoing Survey Modernization Efforts: 2021-2023 Biennium

The results and lessons learned from the initial survey modernization efforts have led to the following ongoing work this biennium:

- Disseminating the survey modernization results to the Oregon Public Health Advisory Board, Oregon Public Health Division and survey leadership, state health programs, community partners, and federal government.
- Facilitating discussions with the Oregon BRFSS leadership about developing the infrastructure and processes to engage communities in designing statewide, locally funded adult surveys (e.g., state BRFSS).
- Establishing and engaging a youth-led, diverse, statewide Youth Data Council to improve the 2022 Student Health Survey, with support from community partners. The Youth Data Council will receive training; make recommendations to improve the survey process, content, messaging, and reporting (e.g., interactive data dashboard); and explore other data sources to provide context and actionable data.
- Coordinating with the Epidemiology and Laboratory Capacity (ELC) funded work examining the broader impact of COVID-19. For that project, OPHD has \$1 million to fund BIPOC community researchers and public health leaders to lead the development of a state data system for tracking a broader set of measures (e.g., social determinants of health, mental health) in a culturally responsive way to be prepared for future pandemics and to inform the statewide health improvement plan. Such a system might use existing data sources, as well as include primary data collection.

Key Lessons Learned for Future Efforts

Working with community-based individuals, leaders and researchers on modernization taught us several lessons that are important for OPHD to consider as it moves forward in further engaging communities in modernization efforts:

- Collaborate with community partners through all phases of the data life cycle. This is essential for improving the representativeness and validity of our data systems and reporting.
- Fund community partners directly and sufficiently for their time and expertise. This includes compensation for adult and youth partners.
- Build budgets and timelines to allow sufficient staff time and resources for relationship building and maintenance. Account for staff time for such activities as facilitating continuous communication among partners, organizing meetings, disseminating materials.

- Communicate regularly and be transparent with community partners (e.g., share datasets, budgets, internal decision-making processes, legal responsibilities).
- Share power with community partners at every possible step. (e.g., share datasets and budgets, cede project review for participant compensation to community research partners.)
- Be flexible, willing to recognize mistakes and change course.
- Avoid overburdening community partners.
- Build organization-wide commitment and infrastructure to support staff and programs to advance equity and undo structural racism reflected in data systems by collaborating with community partners through all phases of the data life cycle. Examples of needed infrastructure include:
 - Training, technical assistance, and ongoing coaching for staff (e.g., conflict resolution, power dynamics, data sovereignty and data justice, decolonizing research, and data, and facilitating difficult conversations) to support program and staff commitment to community engagement.
 - Agency-wide infrastructure for sustained partnerships with the communities to engage in all phases of the data life cycle from design through collection, analysis, and dissemination (e.g., funding, contracts, relationships).
 - Agency-wide assessment and coordination of community engagement activities around data (e.g., how many youth councils/advisory groups are there?).
 - Clear vision for the outcome of data equity efforts.
 - Articulation of the public health system’s future state for data infrastructure that centers communities in all phases of the data lifecycle.
 - Universal understanding of public health data systems now, and where communities are asking public health data to go, with the understanding that some public health surveys will need to continue but have opportunities to improve.
 - Communication
 - Clear guidance on channels of communication within OPHD and with community partners.
 - Campaign or structures to communicate and coordinate all OPHD community equity activities and to align with related OHA activities.
 - Plan to disseminate knowledge and activities, including roles of communities and OPHD, and strategies for clear, consistent, and effective messaging
 - IT support for software and platforms for collaborating across agencies and with communities. (e.g., Google Docs works for many partners but not state staff, not all parties can use Zoom before IT approval at Multnomah County level).

A Possible Model of Modernized Community Health Data System

In contemplating a model for a modernized community health data system, it is important to consider the system as not a group of individual surveys (e.g., BRFSS, SHS), but as a diverse and integrated set of data sources that inform one another, such as:

- Community-led data collection systems for specific-community data and reporting of those data. In this approach, communities identify priorities and play a lead role in design, data collection, analysis, and contextualization of results.
- State data systems for population-based statewide estimates and reporting that include a sustainable, coordinated system for authentic community engagement to ensure the communities are represented in the surveys and questions are culturally appropriate. For example, a state BRFSS could provide statewide estimates and improve on the CDC BRFSS methods based on community input, the BRFSS statewide pilot, and scientific research. Including minimal community led standards for reporting race, ethnicity, language, disability, sexual orientation, and gender identity (REALD & SOGI).
- Federally funded population-based surveys required for federal reporting (e.g., CDC BRFSS) and useful for supplementing local data systems (e.g., Household Pulse Survey). While OPHD does not have the power to change these systems, they can provide recommendations to our federal funders and their advisors.
- Local complementary surveys (e.g., panel surveys, Facebook surveys) that are quick to implement and less expensive, but not necessarily representative of all adults in Oregon.

**Public Health Advisory Board
Strategic Data Plan Subcommittee**

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I. Background

The Public Health Advisory Board (PHAB) is established by ORS 431.122 as a body that reports to the Oregon Health Policy Board (OHPB). The purpose of the PHAB is to be the accountable body for governmental public health in Oregon.

The role of the PHAB includes:

- Alignment of public health priorities with available resources.
- Analysis and communication of what is at risk when there is a failure to invest resources in public health.
- Oversight for Oregon Health Authority, Public Health Division strategic initiatives, including the State Health Assessment and State Health Improvement Plan.
- Oversight for governmental public health strategic initiatives, including the implementation of public health modernization.
- Support for state and local public health accreditation.

Since 2016, PHAB has established subcommittees that meet on an as-needed basis in order to comply with statutory requirements and complete deliverables. PHAB currently has three subcommittees:

- 1. Accountability Metrics Subcommittee**, which reviews existing public health data and metrics to propose biannual updates to public health accountability measures for consideration by the PHAB.
- 2. Incentives and Funding Subcommittee**, which develops recommendations on the local public health authority funding formula for consideration by the PHAB.
- 3. Strategic Data Plan Subcommittee**, which makes recommendations for a public health system plan for the collection, analysis and reporting of population health data based on community participation.

This charter defines the purpose, scope, and deliverables for the PHAB Strategic Data Plan Subcommittee.

II. Purpose:

In October 2020, PHAB adopted its current [Health Equity Review Policy and Procedure](#), which reflects PHAB's values and a commitment for the public health system to lead with racial and ethnic equity.

Public health data are used to make program, policy, and funding decisions. Public health data are needed to identify and eliminate health inequities. A primary function of state public health is to collect and report public health data for these purposes. Public health data are used by federal, state, local and Tribal public health authorities, health care, researchers, community-

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based organizations, other government agencies, and community members. Therefore, data must be accurate, accessible, and reflect community values and wisdom.

The PHAB Strategic Data Plan Subcommittee will be responsible for helping to create, through recommendations and feedback from community partners, a strategic data framework. The goal of this framework is to establish the parameters of public health data that accurately represents and addresses the vision and mission of our community partners and the agency.

This subcommittee will build on existing feedback and the knowledge of members to develop priorities for public health data systems across the continuum of public health data types. This will include engaging with governmental and community public health partners to review recommendations and the framework. OHA and Public Health will communicate to the Subcommittee what changes they can implement from the framework to establish an implementation timeline. This framework will be incorporated in the foundation of the 2023 State Health Assessment and other data infrastructure projects as OHA is able.

Accountability and ongoing monitoring will be the responsibility of the PHAB Accountability and Metrics subcommittee.

III. Community-Based Participation

In this effort, community-based partnerships and Local Public Health Authorities have been identified as purveyors and/or users of public health data. Community members include representatives from the communities of color and tribal communities community, people with disabilities, immigrants and refugees as well as representatives from the LGBTQIA2 communities¹.

Additionally, the following entities have been identified for this effort:

- Local Public Health Authorities
- Community-based organizations
- Coordinated Care Organizations
- Health care providers
- Oregon academic entities
- Other government organizations

Oregon Tribes are also users of public health data, and OHA will engage with Tribes formally on public health data and through the representative of Oregon Tribes on the Public Health Advisory Board.

¹ The PHAB Strategic Data Plan Subcommittee is a public meeting and provides a voice to community members and the population at large.

IV. Deliverables

1. Framework for advancing public health data toward better reflecting Oregon's residents through co-developing questions in ways that are sensitive to context, increased validity and precision, context-sensitive interpretation, to result in increased usability of this data by data users, including community members.
2. Identifying relevant values and goals for public health data.
3. Recommended shifts in PHAB accountability metrics.
4. Guiding principles on incorporating these values into the continuum of public health data, from data where the Public Health Division has a high degree of authority and control, to those areas where it does not.
5. Principles to guide community leadership and oversight in community engagement and participation.
6. Outline guiding principles that inform other Public Health Advisory Board subcommittees in their work regarding data collection, metric development and data interpretation to work toward health equity and data justice. This can be regarding types of public health data collected or processes regarding data.
7. Recommendations on how to transform Oregon's public health data systems to center equity and data justice.

Items that are out of scope for this subcommittee:

- information technology infrastructure
- Recommendations on individual public health data systems or data sets
- Funding recommendations

V. Subcommittee member responsibilities

- Regularly attend meetings and communicate with OHA staff to the subcommittee when unable to attend on a regular basis.
- To the extent possible, review meeting materials ahead of time and come prepared to participate in discussions.
- Share relevant information with one's own organization or with other groups as relevant.

Members join either via a public facing selection process for one of (xx) public seats. PHAB members are encouraged to participate in one or more subcommittees of their choosing.

V. Resources

This subcommittee is staffed by the OHA Public Health Division:

- Cara Biddlecom, Deputy Public Health Director and Director of Policy and Partnerships
- Victoria Demchak, Health Equity Coordinator
- Diane Leiva, Public Health Division Data Interoperability Coordinator
- Virginia Luka, Data Justice Policy Analyst

Other leaders, staff, and consultants as requested or needed.

DRAFT FOR DISCUSSION: High level outline for PHAB Framework for Modern Public Health Data

May 29, 2022

1. Introduction
2. Acknowledgments
 - Survey modernization partners
3. Executive Summary
4. Values for modern public health data (with definitions)
 - Data justice
 - Data sovereignty
 - Dismantling white supremacy in public health practice
 - PHAB Accountability Metrics Shifts
5. Components of the public health data system
 - Framing: where we are today and where we need to move
 - Framing: dependencies on other public health system partners
 - Race, Ethnicity, Language and Disability (REALD) data
 - Sexual Orientation and Gender Identity (SOGI)
6. Continuum of public health data
 - Community-led data collection systems
 - State data systems for population-based statewide estimates
 - Federally-funded population-based surveys
 - Local complementary surveys

Summary of Survey Modernization Community Specific Reports

The Survey Modernization community-specific reports in 2019-2021 was a review of existing data to identify how representative that data was, how it could be improved, and identify community priorities for improvement in collection and interpretation. In working across four groups, differences in data requested and interpretation highlighted the needs for greater engagement with different culturally specific communities. Each group developed their own report, though the Latino and Black groups worked together on their report, resulting in three reports.

This focused on two specific survey tools: the Behavioral Risk Factor Surveillance System (BRFSS) and the Oregon Healthy Teens/ Student Health Survey (OHT/ SHS) for youth of high school age. Data generated from these two surveys are used for targeting services, securing grant funding, addressing emergent health issues, informing legislation and measuring progress toward public health objectives.

The BRFSS is part of a national survey that is defined and partially funded from the Centers of Disease Control and Prevention (CDC). Multiple public health programs have funding contingent on using the BRFSS; some state and county programs also use the information in applying for funding for federal and other funders. The state carries out the survey annually, with a racial and ethnic oversample conducted every few years as an attempt to gather sufficient participation from communities of color and tribal communities. Currently the survey has several challenges, including insufficient representation of communities of color and tribal communities, a high cost to implement, lack of estimates for smaller geographic areas, and a long length averaging over 24 minutes. Further, there are concerns about representativeness and lack of community engagement in survey design, analysis, interpretation of results and dissemination of findings.

Those challenges were the impetus to develop these reports with these four communities. OHA/ PHD hoped to develop better information and provide the following:

- Understanding and interpreting BRFSS and OHT/SHS survey data;
- Identifying strengths, gaps and limitations of BRFSS and OHT/ SHS data and methods;
- Facilitating community-led data collection on identified gaps in the data; and
- Developing recommendations toward sustainability of these tools.

Below is a summary on each of the reports (1) American Indian/ Alaska Natives; (2) Black and Latinx communities; (3) Pacific Islander communities.

1 – American Indian/ Alaska Natives.

Summary for “Oregon Tribal Survey Modernization Project: Northwest Portland Area Indian Health Board Northwest Tribal Epidemiology Center (NPAIHB), Final Report to Oregon Health

Authority.” July 2021. Report available here:

<https://www.oregon.gov/oha/PH/ABOUT/TASKFORCE/Pages/Community-Reports.aspx>.

Overview of project: Review survey data from the Oregon Behavioral Risk Factor Surveillance System (BRFSS) and Oregon Healthy Teens (OHT) to highlight priority analyses, identify knowledge gaps and generate topics and methods to provide additional context to the results for AI/AN communities in Oregon.

Methods: This project conducted a critical examination of Tribal BRFSS survey methods and supplemental data. Five participants were recruited to work with four staff of the Tribal Epi Center, drawing from a call for participation to all Oregon Tribes.

Note that the data analyzed is different than what we see at the state, since the Tribal Epi Center manages the BRFSS and other surveys for Tribal members and urban Indians in Oregon. The Tribal Epi Center owns this data.

This group identified the following challenges:

- **Defining AI/AN:** It’s challenging to accurately identify race for AI/AN people. Mischaracterization of race happens for 10-60% of AI/AN individuals; those people are generally mischaracterized as white. This workgroup felt strongly that the primary role of improving BRFSS and OHT data for AI/AN communities should be to better inform and serve Oregon tribes, rather than increasing accuracy for researchers.
- **BRFSS methods:** When these surveys are conducted by OHA, there is insufficient outreach and trust, resulting in poor engagement with AI/AN communities.
- **Tribal use of BRFSS data:** This data has primarily been useful at the county level, but difficult to aggregate across counties for Tribal use. The data is commonly used by counties in applying for funding; this could be a conflict with Tribal agreements for data. This team suggests that OHA would be better served by increasing funding for known needs rather than improving surveys.
- **Lack of meaningful context:** Resulting data lacks useful context that would inform action. This group identified focusing on not just negative or behavioral factors for the youth survey, but also protective factors, including involvement in cultural/ Tribal activities.
- **Invest in tribal specific BRFSS surveys:** NPAIHB and NWTEC presently support tribes to conduct specific BRSS surveys that allow Tribes to have full ownership of the data, ask questions relevant to their tribe and community and reach tribal members effectively and efficiently. Tribes have invested in the staff and infrastructure for past surveys and resulting data has provided relevant and actionable information about the needs of Tribal members.
- **Data use and literature review:** Data on tribal members can be taken out of context when interpreted and reported by entities outside of a Tribe. This review identified two specific types of misinterpretations: (1) insufficient context in data on student absenteeism, since it did not include factors that may increase absenteeism and the cultural norms that may affect absenteeism; (2) poor analysis through the “best race”

methodology used by OHA, which can diminish the appearance of health disparities and hide burdens by multi-racial respondents.

This group made the following recommendations to OHA (much of this is a direct quotation from the report

- Data needs to be actionable:
 - o Work with Tribes, UIHP and NWTEC to convene future discussions with stakeholders to better understand data priorities and the need for locally actionable, tribal-specific data
 - o Incorporate non-western approaches to health and health care in surveys.
- Survey methods
 - o Partner with tribes and tribal/ urban AI/ AN organization to increase BRFSS participation and educate community members on BRFSS/ OHT
 - o Include questions on protective factors, particularly involvement in tribal and community activities.
- Tribal and AI/AN community engagement
 - o Support Oregon tribes in conducting tribal BRFSS surveys'
 - o 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 AI/AN communities.

2: Black and Latinx Communities

“Engaging communities in the modernization of a public health survey system” Prepared by Dr. Kusuma Madamala, Tim Holbert from Oregon Health Authority; Dr. Andres Lopez and Dr. Mira Mohsini from Coalition of Communities of Color. June 2021. Report available here:

<https://www.oregon.gov/oha/PH/ABOUT/TASKFORCE/Pages/Community-Reports.aspx>

Overview of project: This specific project assembled two 4-5 person culturally specific project teams through a series of interview. These teams comprised research and practice-based partners with lived experience from two groups: the African American, African Immigrant and Refugee community and Latinx communities. This process was co-facilitated by the Coalition of Communities of Color. The two teams met separately throughout the process then convened for the last two meetings, agreeing to report their work together because of the overlap between areas of interest (mental/ behavioral health and health care access) and the limitations on gathering and community engagement from COVID.

Findings: Both teams share the concern that both survey tools reproduced the assumptions, norms and methodologies of white dominant culture, and thus created further harm by misrepresenting racial and ethnic populations. Observations and critiques beyond this were in six themes

1. Lack of meaningful context: Survey results lacked the necessary context to make results meaningful and appropriately actionable. Team members often reported that the survey questions failed to consider social and cultural conditions and thereby compromised data quality.
2. Intersectionality: Project teams were adamant that it is essential that individuals are complex and live and have identities within multiple overlapping and often politicized and/or socially charged structural conditions that shape their everyday experiences. Minimally data needs to be disaggregated by race, ethnicity, income, age, primary language and country of birth.
3. Actionable data: Questions need to be worded so that they produce data that accurately leads to direct action meaningful to the community.
4. Sample size and response rate: Teams were very concerned about the low response rate among BIPOC community members. BRFSS telephone survey methods call landlines and administer surveys in English, biasing survey results toward older white people. Teams recommended engaging community members in question development and administration of survey to their own community. They also asked that the “small numbers” (i.e., an insufficient sample size for representative data) not limit sharing data with communities, since that can create distrust. Further, they urged restraint on creating comparison tables across demographics.
5. Integration of other data sources: project teams requested access to data from other collection systems to provide more context for BRFSS and OHT/ SHS data, including vaccination data (from the Alert IIIS) and free and reduced lunch data from Oregon Department of education.
6. Translation and health literacy: Project team members were concerned that Spanish speaking Oregonians might not understand questions due to translation. They were also concerned about formal and complex language and recommended translation to “plain language” meaning words at a sixth grade reading level. The group suggested an external advisory group specifically for translation.

Other lessons learned:

- Community engagement is critical for scientific integrity for the data. Without it, the validity of the data is questioned, and it limits the relevancy, generalizability and use of the data.
- Accountability: These surveys track individual behavior. But individual behavior is influenced and can be determined by the context of an individual. Without context, this data is not actionable. And without knowing the systems that are affecting behavior, public health agencies cannot be held accountable for public health improvement, the systems they uphold and the public they serve.
- Building trust through equitable partnership and data practices: OHA staff learned much about needed practices to help build trust with community partners. These practices supported the partnership:
- Avoid future harm caused by the following:

- a lack of qualitative research, individual behavior questions without social context that shift responsibility for wellbeing onto the individual, and lack of questions in the BRFSS about behavioral and medical care beyond mainstream western medical sources.

Recommendations and next steps:

- Build in time and resources necessary for relationship development between governmental public health and community partners in data
- Continue long-term sustained, compensated community-led data collection
- Conduct a minimal BRFSS – explore lessons from the CA Helath Interview Survey (CHIS)
- Integrate community leadership in survey development, administration, analysis and use
- 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
- Establish a survey translation advisory committee
- Demonstrate transparency in how BRFSS and OHT data is used by OHA and by others
- Engage and defer to community-based organizations and /or regional health equity coalitions in survey administration
- Re-engage the health equity researchers of Oregon (HERO) group
- Investigate county health rankings and BIPOC data hubs as possible conceptual frameworks for 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.

3. Pacific Islander Community

“This is the Way We Rise: Pacific Islander Data Modernization in Oregon 2021” was written by the Oregon Pacific Islander Coalition, with contributions from multiple Pacific Islander leaders, researchers, community organizations, language experts, and Program Design and Evaluation Services survey modernization staff. A complete list of contributors can be found on page 6 of the report. The report and data are owned by the Oregon Pacific Islander Coalition.

Report here: <https://www.oregon.gov/oha/PH/ABOUT/TASKFORCE/Pages/Community-Reports.aspx>

Overview of project: The Pacific Islander Data Modernization (PIDM) was led by Pacific Islander community organization leaders and researchers brought together by the Oregon Pacific Islander Coalition (OPIC) with the support of state and county staff. Due to the lack of reliable disaggregated data regarding the health and wellness of Pacific Islanders in Oregon, leaders decided to build upon recommendations and lessons learned from Multnomah County’s Pacific Islander Data Project (PIDP). The remarkable work of PIDM led to the development of the

Pacific Islander Health, Equity, and Liberation (PI HEAL) Assessment which was used as the primary data collection tool that honors Pacific Islander ways of knowing and being.

Methods:

The Oregon Pacific Islander Coalition required the Oregon Health Authority's Public Health Division to enter into a data sovereignty agreement to outline aspects such as power structures, ensure Pacific Islanders served as research, engagement, and language experts, provide proper compensation for all participants involved from start to finish, and establish data ownership and usage.

A core research team was responsible for the overall project development and management, including community engagement, leading data collection and analysis, and providing community based participatory research training and support.

Seven Pacific Islander led community-based organizations served as high-level advisors, hosted data workshops and assisted with outreach.

Ten community research workers co-developed and co-facilitated data workshops and assisted with data analysis.

Seven data workshops were virtually hosted in order to collect meaningful qualitative data to contextualize the PI HEAL Assessment, as well as uplift data and research capacities within our Pacific Islander community. During the workshops, participants were asked to complete the survey and then gathered in small groups to discuss their feedback regarding their survey responses and their experience with the survey. Participants were each compensated \$75.

The PI HEAL Assessment was provided in 'Ōlelo Hawai'i, Pohnpeian, Tongan, and English. 136 Pacific Islander members responses to the PI HEAL Assessment.

Responses to the PI HEAL Assessment were analyzed using IBM SPSS. The data workshops were recorded by notetakers and Zoom recording. The community research workers and core research team conducted thematic coding and co-developed diagrams to highlight narratives connected to the overall health and wellbeing of our Pacific Islander community.

Challenges:

- **Lack of disaggregated data collection and representation:** In health data systems, Pacific Islanders tend to be categorized under the larger umbrella term of Asian Pacific Islander despite the different nationalities and cultures. According to the 2010 census, Pacific Islander population was the fastest growing racial or ethnic group in the United States (US), while the 2019 US Census' American Community Survey indicate that Oregon is one of ten states in the US with the largest Pacific Islander populations including Hawaii, California, Washington, Texas, Utah, Florida, Nevada, New York, and Arizona.

- **BRFSS:** The BRFSS does not provide reliable data for our Pacific Islander communities. During an attempt to conduct an oversample, the BRFSS was only able to collect responses from 106 Pacific Islanders during a three-year period.

Recommendations:

- Map PI HEAL Assessment community health factors to the State Health Improvement Plan to leverage existing resources and being immediately addressing the health needs raised in this work.
- 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.
- Continue to celebrate, uplift and invest in the vast brilliance of the people of Oceania.

Summary to Participatory Analysis: Expanding Stakeholder Involvement in Evaluation by Veena Pankaj and Myia Welsh (April 2011)

Question: What are the best ways to involve stakeholders in evaluation? Are there opportunities for participation in evaluation that could be made more widely available?

Background: Participatory evaluation began in the 1960s and gained momentum in the 1980s. The premise is to involve program stakeholders in the evaluation process – make them active participants rather than passive subjects and draw on the wisdom of the people implementing the programs – thus a learning opportunity.

Benefits:

- Inform the evaluation with multiple insider perspectives.
- Ensure mutual understanding between the evaluation team and program stakeholders of the program's intended goals, strategies, and desired outcomes – and the purpose of the evaluation.
- Make evaluation results more useful for communications, fundraising and program improvement.

How To Use Participatory Analysis and Interpretation?

- Present first draft of data/findings giving the stakeholders the chance to provide context and input in findings and recommendations (What is missing?).
- Help sustain stakeholder interest and engagement in the evaluation process.
- Identify which findings are the most meaningful to stakeholders; and
- Increase likelihood that findings and recommendations will be put into practice.

Generally, the participatory analysis is prepared for and facilitated by the evaluator. The evaluator prepares agenda and presentation materials to elicit discussion.

Examples of Participatory Evaluations:

1) Data Placemats for Improving Reporting

- a. Data was synthesized and organized into topic areas emergency from preliminary analysis and evaluation goals. Each placemat presented data through charts, graphs, and quotes. The purpose of the placemat is to allow stakeholders to independently ponder and analysis data. It is up to the evaluator to decide which data will be included, and how to effectively organize and display.
- b. Outcome – More comprehensive, detailed reports that told a more accurate story. Simplified final report. Evaluators and stakeholders discussed and agreed to findings, preliminary data visualizations to create the placemats. Fewer drafts were exchanged.
- c. Visual Presentation of the Data – The evaluator should provide an unbiased analysis of key data, organized by evaluation question, outcome, or other topics. Visualizations should aid stakeholders to understand relationship among the data.

- d. Cost – Preparation of participatory analysis takes time and should be included in the estimate of the evaluation project workload.

2) *Setting Realistic Expectations and Increasing Support with Stakeholders*

- a. Data collected from grantee reports, media scans and program participant interviews.
- b. Data compiled in preliminary thematic categories so to present data in comprehensible but unbiased fashion.
- c. Format – Visual slideshow of the data, formatted into charts and graphs to facilitate discussion.
- d. Outcome –
 - i. Increased clarity
 - ii. Improved understanding of data and its limitations – what can realistically be drawn from the data
 - iii. Buy-in and support for findings and recommendations
 - iv. Simplified final report
 - v. Improved evaluator-stakeholder communications and relationship, and
 - vi. Improved stakeholder confidence in using the data for reporting and fundraising.
 - vii. Including stakeholders in the analysis reinforced that their perspective was vital to understanding the data.

3) *The Importance of Who is at the Table*

- a. Targeted “Inside” (government/institutions) and “Outside” (in the field)
- b. Data collection included: Surveys, Informant Interviews, Focus Groups and Document Review – Primarily Qualitative Data (Open-ended surveys and interview data).
- c. Preliminary findings organized by evaluation questions and supported by verbatim quotes.
- d. Goal – To elicit stakeholder feedback on preliminary findings and gather input to recommendations. Two meetings were organized.
- e. First Meeting –
 - i. Slideshow used to present findings and participants were give hardcopy of full findings. Table cards with guiding questions were available. Three questions to guide discussion:
 - 1. How does this information align with your experience and perceptions?
 - 2. What doesn’t fit? How?
 - 3. Where would you add context to clarify or explain findings?
- f. Second Meeting –
 - i. Focus was on recommendations gleaned from the data. What recommendations are most relevant to continuing the work’s priorities and resources.
 - ii. The final recommendations were considered the most relevant, useful, and actionable.
- g. Outcome – The art of participatory analysis is deciding Who is at the Table? Participants need to be able to have a conversation of depth nor breadth and should be in an action/decision making position, capable of speaking for the organization.

- h. Cost – Participatory analysis is time consuming. Meetings can be intense and require facilitation. Depending on how much information is presented, it may be preferable to split the session across two days: review findings and firm up recommendations.

Participatory Analysis: Getting Started

- Quality – How might participatory Analysis improve the quality of findings/recommendations?
- Stakeholders – What might be the positive outcomes of engaging evaluation stakeholders?
- Timeline & Resources – Will the participatory analysis approach fit within the project timeline and available resources.