

AGENDA

PUBLIC HEALTH ADVISORY BOARD Strategic Data Plan Subcommittee

November 15, 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: Cara Biddlecom, Diane Leiva, Victoria Demchak, Virginia Luka

| | | |
|----------------|--|--|
| 1:00 – 1:15 pm | Welcome and Introductions <ul style="list-style-type: none">• Welcome members and staff• Highlight related reading• ACTION: Approve September meeting minutes | Victoria Demchak and Virginia Luka, Oregon Health Authority |
| 1:15 – 1:35 pm | BRFSS and Survey Modernization introduction <ul style="list-style-type: none">- Survey modernization resources- BRFSS overview- Please review recording of May 2021 PHAB meeting survey modernization presentation by partners: https://youtu.be/LEQN7kCy7rk- Objective: Build understanding of community feedback to BRFSS and community data collection systems. | Dean Sidelinger, Oregon Health Authority |
| 1:35-1:50 pm | Public health data modernization framework <ul style="list-style-type: none">- Discuss focus and components- Objective: Determine whether this feels appropriate, determine any areas of priority. | Victoria Demchak and Virginia Luka, Oregon Health Authority |

1:50 – 2:00

Public comment

2:00

Adjourn

PUBLIC HEALTH ADVISORY BOARD

Strategic Data Plan Subcommittee

September 20, 2022

1:00 - 2:00 PM

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

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

Other visitors:

Welcome and introductions

Subcommittee members and staff introduced themselves.

Minutes approval

Meeting minutes were approved with all subcommittee members in favor.

Strategic Data Plan subcommittee charter review and possible approval

The subcommittee discussed the equity and inequity wording within the charter and the original intention of the subcommittee, which is to improve the accuracy and accessibility of public health data so it can be used to promote equity through funding, policy and program decisions. The subcommittee made edits to the charter to reflect strengths-based wording.

Subcommittee members reviewed the updates to the deliverables section of the charter and made some additional changes for clarity and intention to center communities.

Additional clarifying edits were made to the charter.

The subcommittee unanimously approved the revised charter with the edits provided today. The charter will be approved to the Public Health Advisory Board at the October meeting.

Veronica reminded the subcommittee that more changes can still be made to the subcommittee charter and asked for a subcommittee member to present it to the Public Health Advisory Board. Jackie volunteered to present to charter to PHAB and take any additional feedback at the PHAB meeting.

BRFSS and Survey Modernization introduction

This agenda item will be carried over to the October meeting.

Public Comment

No members of the public were present, so no public comment was provided.

Meeting adjourned at 1:58 pm.

DRAFT

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.

The Student Health Survey – Update for Community Partners

The 2022 Student Health Survey focuses on equity

The 2022 Student Health Survey (SHS) is different from previous youth surveys. Community feedback supports and intensifies the need for the Oregon Public Health Division (OPHD) and the Oregon Department of Education (ODE) to focus on equity. Equity is a right, not a privilege, for all Oregon Youth. Oregon Health Authority (OHA) defines health equity as “...when all people can reach their full health potential and well-being and are not disadvantaged by their race, ethnicity, language, disability, age, gender, gender identity, sexual orientation, social class, intersections among these communities or identities, or other socially determined circumstances. Achieving health equity requires the ongoing collaboration of all regions and sectors of the state, including tribal governments to address: The equitable distribution or redistribution of resources and power and recognizing, reconciling, and rectifying historical and contemporary injustices.”¹

Not only should OHA services be equitable but our methods for collecting and disseminating data should reflect equity as well. To be truly equitable, the Student Health Survey needs more than the revision of a few questions. It needs community and youth engagement from design through the communication of results. It needs fundamentally different and contextualized questions that meet the needs of health programs and communities. It needs structures within OPHD that support community engagement and leadership. To be fully equitable, the SHS needs OPHD to change the way that it works. This requires organizational change which can be challenging and will require sustained effort and leadership.

This update summarizes the collaborative work of Program Design and Evaluation Services (PDES)² with community organizations to bring more equity to the design and content of SHS and efforts to shift the way that OPHD engages community.

Community perspective sheds light on the path

OHA’s goal is to eliminate health disparities by 2030. What does that mean? Some groups of people experience persistent differences in health and health care that stem from broader systemic inequities, such as unequal distribution of social, political, economic, and environmental resources which result from racism and discrimination. Our goal is to ensure that everyone has the same opportunities to be healthy.

Beginning in the spring of 2019, the OHA Public Health Director’s Office began collaborating with the Oregon Pacific Islander Coalition (OPIC), the Coalition of Communities of Color (CCC), and the Northwest Portland Area Indian Health Board (NPAIHB) to modernize Oregon’s population health surveys. These community organizations provided a deep community-centered critique of the purpose, design, and implementation of the surveys and developed a set of actionable recommendations for OHA for authentically engaging with communities through all phases of the data life cycle from design through analysis and dissemination.

¹ <https://www.oregon.gov/oha/oei/pages/health-equity-committee.aspx>

² <https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/programdesignandevaluation/services/pages/index.aspx>

The Student Health Survey – Update for Community Partners

PDES collaborated with CCC and the NPAIHB to form and facilitate community-specific data project teams for the Latinx, Black/African American/African Immigrant & Refugee, and American Indian/Alaskan Native communities. Project teams used community-identified priorities to guide the analysis, interpretation, and contextualization of student youth data. Some partners also led community-driven data collection on topics and methods of their choice.

OPIC and PDES worked together to build capacity among Pacific Islander researchers, community organizers, individuals, and community-based organizations (CBOs) to conduct community-led data collection and research. A Pacific Islander core team of researchers worked with PDES and sought guidance from various advisory groups including OPIC. 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 approach³ with a broader team of Community Research Workers.

In addition to providing key recommendations on the content of the SHS, OPIC, CCC and NPAIHB gave recommendations on including community at every step of the process of creating data from survey design through dissemination. PDES operationalized these recommendations by standing up a Youth Data Council (YDC) to give input (and ultimately collaborative decision making) into the design, content, and dissemination of the SHS. The community partners have given ongoing feedback on the formation and support of the YDC. Community partners also met with the SHS Advisory Committee in November and December 2021 to discuss their findings and recommendations. This launched the process of modernizing the SHS.

Community partners worked with PDES to write comprehensive reports describing their findings and recommendations. You can learn more about this work and read the final reports [here](#).

These same community organizations have been instrumental in disseminating the findings from the community-led data projects. Community partners have collaborated with PDES in presenting the findings in multiple venues including (but not limited to) the Public Health Advisory Board (PHAB)⁴ and OPHD Science and Epidemiology Council.

The recommendations from the community were eye-opening.

We heard that the way many of the survey questions are asked and reported does not help and, in fact, causes harm to Oregon youth. The main criticisms of the survey are:

- Tribal and Indigenous youth, youth of color, non-binary identifying youth, and non-heterosexual youth, have historically been under-represented, marginalized and lack visibility and a voice in the survey.
- Survey questions do not provide communities with enough information, context and understanding of systemic barriers such as racism, and discrimination faced by Oregon youth.

³ Pankaj V. et.al. “Participatory Analysis” 2011 accessed at https://www.innonet.org/media/innovation_network-participatory_analysis.pdf on 5/13/22

⁴ A recording of the presentations is available at: <https://www.youtube.com/watch?v=LEQN7kCy7rk> (survey discussion starts at the 52.50 minute mark and is about 90 minutes in length).

The Student Health Survey – Update for Community Partners

- Survey questions should focus on youth’s strength and resilience, rather than negative outcomes that reinforce blame on individuals.
- Survey questions should focus on systems and environments in which youth make choices rather than entirely on decontextualized individual behaviors which have the effect of blaming youth rather than addressing the systemic causes.
- The design of surveys should include youth voice and youth as decision makers in the process.
- Survey questions do not provide enough contextual data to result in meaningfully actionable analysis.

What is Survey Modernization?

Survey Modernization simply means that we’re working to make the survey better. For everyone. We’re taking community recommendations on how to improve the survey and putting them into practice. We are working to reimagine the survey questions and capture data that is more relevant to youth’s lives to help provide the support they need to succeed.

Goals and priorities for the 2022 SHS

Based on the recommendations from community and input of the YDC, we created an action plan for revising the SHS. Primary among our goals were to (1) revisit the purpose of the SHS to ensure that it aligns with our equity focus, (2) stand up a youth data council to provide input and guidance on the content, (3) create criteria for prioritizing survey questions (detailed on the following page) and (4) make the survey more accessible by reducing the number of questions.

The Student Health Survey – Update for Community Partners

SHS Content Work Group Membership

An SHS Content Work Group met regularly throughout 2022 to develop the 2022 SHS questions. Group members consisted of the following representatives from the Oregon Health Authority (OHA), Health Services Division (HSD), and the Oregon Department of Education (ODE):

Oregon Health Authority

Tom Jeanne, Deputy State Epidemiologist
Renee Boyd, Program Design and Evaluation Services
Victoria Buelow, Health Promotion and Chronic Disease Prevention
Meghan Crane, Injury and Violence Prevention
Sarah Knipper, Adolescent and School Health
Alexis Phillips, Adolescent and School Health
Kristen Rohde, Program Design and Evaluation Services
Dagan Wright, Injury and Violence Prevention

Health Services Division

Shanda Hochstetler, Child and Family Program
Roxann Jones, Problem Gambling
Michael (My'kee) Martinez, Tribal Alcohol, Tobacco and Other Drugs Prevention Specialist
Fran Pearson, Child and Family Program

Oregon Department of Education

Grace Bullock, Senior Mental Health Officer, Office of the Director
Josh Rew, Psychometrics and Validity, Department of Accountability
Renee Roman Nose, Native American Student Success Coordinator, Office of Indian Education

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How were questions selected?

The SHS Content Work Group prioritized questions based on the following criteria:

- **Accountability:** Is OHA or ODE accountable for providing the information? Does it support a legislative concept or policy related to youth health or education? Does it address an emerging issue?
- **Health Equity and Social Justice:** Does it align with [Healthier Together Oregon \(HTO\)](#) or [Student Success Act \(SSA\)](#) priorities related to institutional bias, adversity, trauma and toxic stress, or economic or social determinants of health (housing, food security, etc.)?
- **Systems-focused:** Does it address the context or environment in which students live? Is it culturally appropriate?

SHS Content Prioritization Guide

Purpose: The Prioritization Guide will be used as part of a transparent process to identify the critical topic areas and questions for inclusion in the Student Health Survey.

| | Equity-focused | Individual vs. System-focused (Tribal, Community, Youth Priority) | Public Health or Education Priority |
|--|---|---|---|
| Healthier Together Oregon (HTO) Value | Equity and Social Justice | Strengths-based Empowerment Authentic community input | Accountability |
| Goal | <ul style="list-style-type: none"> • Advances health equity • Aligns with HTO State Health Improvement Plan (SHIP) priorities to address: <ul style="list-style-type: none"> ✓ Institutional bias ✓ Adversity, trauma and toxic stress ✓ Behavioral health (including mental health and substance use) ✓ Economic drivers of health/social determinants of health (including issues related to housing, living wage, food security and transportation) ✓ Access to equitable preventive health care | <ul style="list-style-type: none"> • Culturally appropriate • Age appropriate • Aligns with HTO/SHIP/SSA priority populations <ul style="list-style-type: none"> ✓ Black, Indigenous, people of color, American Indian/Alaska Native people (BIPOC-AI/AN), and emerging bilinguals ✓ People with low incomes navigating poverty, hunger, homelessness or foster care ✓ People who identify as lesbian, gay, bisexual, transgender, queer and questioning (LGBTQ2SIA+) ✓ People with disabilities ✓ People living in rural areas of the state | <ul style="list-style-type: none"> • Addresses current or emerging issues critical to support policy or required for funding • Supports legislative policy related to youth health or education • Required for: <ul style="list-style-type: none"> ✓ CDC grant ✓ Student Success Act (SSA) ✓ Every Student Succeeds Act (ESSA) or other federal education law ✓ Drug-free Communities (DFC) ✓ Community Assessments ✓ Other |

The Student Health Survey – Update for Community Partners

Accomplishments

The PDES SHS and YDC Coordinators worked with the SHS Content Work Group to operationalize the recommendations of the culturally specific project teams facilitated by OPIC, CCC, and NPAIHB. While some recommendations were implemented or operationalized this year, others will require continued effort over the long term.

Accomplishments for this year include:

- Launching the initial YDC to center student voice in the survey as a direct result of community feedback
- Revisiting the purpose and goals of the SHS
- Creating criteria and guidance for prioritizing questions
- Minimizing the burden on youth, and shifting away from blame, by shortening all the questionnaires
 - Removing questions. Examples of questions removed include:
 - Excluding four REALD disability questions (3 new; 1 old) based on YDC feedback
 - Removing all the ACEs questions
 - Finding other sources for data rather than asking youth, for example:
 - Using ODE poverty data rather than asking free/reduced lunch status
 - Using school rather than asking youth
- Including the Everyday Discrimination Scale (short version)
- Increasing the number of REALD categories
- Revising gender identity and sexual health questions to less hetero and cis centric by:
 - Including community-specific gender identities (Two Spirit, Pacific Islander specific gender identities)
 - Asking about “sexual contact” rather than “sex” or “sexual intercourse”
- Making questions more inclusive and less blaming by including answer categories “I prefer not to answer” and “I don’t know what this question is asking”
- Enabling more contextual data by including several open-ended questions such as:
 - What helps you feel healthier, happier, and safer?
 - What is causing you to miss school?
 - What made it hard for you to get your physical health care needs met?
 - What made it hard for you to get your emotional or mental health care needs met?
- Working with YDC to revision and revise the Positive Youth Development questions to be trauma-informed, conceptually integrated, and focused on root causes
- Launching an SHS Data Portal to provide online access to 2020 SHS state- and county-level data for data users

In addition to shortening the survey, the SHS Content Work Group also worked to:

- Ensure that questions provide meaningful context to the challenges our youth face
- Transition from deficits-based questions that focus on the individual to more strengths-based questions that address systemic issues

There’s a lot more work to do moving forward. We’ve divided the work into short-term and long-term goals.

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Short-term Goals

- Reimagine the SHS website to make the results more accessible and engaging to the general public.
- Increase the scope of the YDC membership to include youth who are diverse in terms of race and ethnicity, geography, disabilities, gender identity, sexual orientation, and lived experiences to include different perspectives on the survey.

Long-term Goals

- Expand the inclusion of youth voice via the YDC to include collaborative decision making.
- Continue collaborating with community (including youth) to enhance the value of the data through contextualization and making it more relevant to community needs.
- Continue discussions with federal funders to revise questions that are required for reporting, so they are more focused on systemic barriers and are more culturally appropriate and strengths-based.
- Explore different methodologies or data sources to complement the SHS data and reduce burden on youth.
- Continue conversations on culturally appropriate metrics (e.g., Body Mass Index (BMI) – see Ongoing Improvements below).

This work will involve ongoing discussion, thought and work involving many different partners with different needs. We plan on achieving these goals within the next five years to make the survey more equitable.

The Youth Data Council (YDC) brings students to the table

In March 2022, the first YDC was formed consisting of a small group of Oregon youth attending public school. Community partners helped recruit members for this initial cohort. Due to the limited timeframe for the work of this initial YDC cohort (March to May 2022), they focused on:

- Establishing relationships amongst themselves and shaping how the group would work
- Selecting and refining the design of the SHS Logo
- High-level review of survey content and recommendations with specific focus on questions related to:
 - Disabilities
 - Mental health
 - Gender identity
 - Sexual orientation
 - Racial & ethnic identity
 - Food security

Future YDC cohorts will consist of youth from a broad range of race, cultures, abilities, gender identities, sexual orientations, geography and lived experiences (houselessness, poverty, hunger, etc.). The YDC will convene throughout the school year and will focus on:

The Student Health Survey – Update for Community Partners

- Making the survey more reflective of youth voice and topics of importance related to their health and well-being.
- Developing communications for a variety of audiences (youth, parents, school administrators, local community/general public).
- Making the data on the website more user-friendly and visually appealing to a general audience.

You can learn more about the YDC [here](#).

Ongoing Challenges to Address

The crux of all improvements in our survey systems is having sustainable relationships with community partners. Building and cultivating relationships with partners takes time and resources. Historical structure of OPHD has not considered the importance of supporting community relationship building and sustenance by providing the appropriate level of staffing and resources internally and the mechanisms of funding for appropriate levels of compensation for community partners. This creates a reality in which time, money and resources are typically in short supply in public health, with survey modernization needs colliding with grant and project deadlines and budget constraints.

Other challenges include:

- Constraints on capacity and increased workloads for everyone (community partners, YDC members, OHA and ODE staff).
- The need to balance the desire for collaborating with community partners while being respectful of their time and being able to meet project and task-specific deadlines.
- Lack of a mechanism for compensating community for their time and expertise. The current OPHD contract mechanisms are not sustainable, equitable or accessible, and preference well established and larger CBOs.
- A divisive political climate that often discourages honest, open, and often painful discussions about complex, personal issues such as race, gender identity and sexual orientation and a lack of training for OPHD staff on how to support having those difficult conversations.

Though there are many challenges to this work, PDES is working with OPHD leadership to begin building these infrastructures. Proposed funding for the next biennium includes funding for more community engagement, training, and technical assistance. OPHD leadership is looking into how to support division-wide community engagement.

Ongoing Conversations & Improvements

Clearly, some questions on the survey are problematic in that they are not respectful of diverse cultures (i.e., BMI questions), are insensitive to trauma and privacy needs (i.e., gun access questions), and downplay experiences of racism (i.e., bullying questions). Unfortunately, and despite their inherent flaws, these questions cannot be changed at this time. Some of the questions, such as those on bullying, are required for Maternal Child Health Grant Title V block grant reporting. At our encouragement, programs are beginning discussions with federal grant funders about how these questions are harmful, fail to serve youth, and perpetuate systems of oppression with the hope that funders will allow Oregon to adapt these questions to better serve the needs of youth, communities and OPHD programs.

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Other questions, such as BMI, require more ongoing conversations within the SHS Content Work Group about the relative value of such questions. For example, BMI calculations are derived from height and weight questions. While BMI is used to estimate the percentage of the population who fall into different weight categories and is used in public health as a measure of obesity in the population, it fails to consider differences in frames and body types that are more typical of different racial and ethnic groups. The challenge for programs is that, while it is a flawed metric, it is the only measure that programs have track population obesity. Discussions and exploration of alternative measures with community will continue.

Final thoughts

OHA's goal to eliminate health disparities by 2030 is our north star that guides the work we do. This involves change on a magnitude that we have not seen previously. The COVID-19 pandemic shed light on the disparities that have been deeply rooted in our systems and society as a whole for centuries.

Rebuilding the Student Health Survey to be equitable is more than revising the content, it is about changing the process for how it is built. It is about engaging communities start to finish and that entails changing the organization of OPHD and OHA to support community engagement. Organizational change is a long and difficult task.

While we are proud of the accomplishments made over the past couple of years, we acknowledge that there's much still to do to make the survey more relevant and useful for everyone. It will take time and involve a lot of hard work and difficult discussions. And, despite our best efforts, we will make mistakes. We will appreciate being called out when needed, apologize for any mistakes made and unintended consequences, and continue moving forward. We are committed to making Oregon a better place for everyone. We'll learn, grow, and work together to make sure we better serve all Oregon youth.

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.