AGENDA

PUBLIC HEALTH ADVISORY BOARD
Strategic Data Plan Subcommittee

May 17, 2022
1:00 - 2:00 PM

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Subcommittee members: Jackie Leung, Gracie Garcia, Hongcheng Zhao, Rosemarie Hemmings, Veronica Irvin

Time	Item	Presenter
1:00 – 1:15	**Welcome and Introductions**	Diane Leiva, Oregon Health Authority
1:15 – 1:50	**Strategic Data Subcommittee Rescope of Work** • What we learned • Developing a framework for a Strategic Data Plan	All
1:50 – 2:00	**Public comment**	
2:00	**Adjourn**	

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 communities[2], (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

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[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. BFRSS 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 considers 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.

Engaging Communities in the Modernization of a Public Health Survey System
June 2021

Prepared by:

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EXECUTIVE SUMMARY

Background

Oregon public health programming relies on survey data gathered by the Behavioral Risk Factor Surveillance System (BRFSS) for adults and the Oregon Healthy Teens (OHT)/Student Health Survey (SHS) for youth. Data generated by these two population health surveys is used to target services, secure grant funding, address emergent health issues, inform proposed legislation, and measure progress toward public health objectives.

BRFSS is part of a national survey with some funding from the Centers for Disease Control and Prevention (CDC). Additionally, federal funding for some state programs is contingent on using BRFSS. Every few years, a racial and ethnic BRFSS oversample is conducted in Oregon to make sure there are sufficient numbers of participants from Black, Indigenous, and People of Color (BIPOC) communities for analyses. Current challenges with BRFSS include the high cost to implement, lack of estimates for smaller geographic areas, its length averaging over 24 minutes, concerns about representativeness, and lack of community engagement in survey design, analysis, interpretation of results or dissemination.

The OHT/SHS is not part of a national youth survey, but federal funding for some state programs is contingent on using OHT/SHS. A racial and ethnic oversample is not done. Similar challenges are present for the OHT/SHS as for BRFSS.

Purpose of the Project

The primary purpose of this project was to update our BRFSS and OHT/SHS data systems by providing an opportunity for community partnership and leadership in (1) understanding and interpreting BRFSS and OHT/SHS survey data; (2) identifying strengths, gaps and limitations of BRFSS and OHT/SHS data and methodologies; (3) facilitating community led data collection on identified gaps in the data; and (4) developing recommendations for avenues for sustainability.

This report focuses on the work with the African American, African Immigrant and Refugee, and Latinx populations. There are other reports that focus on the American Indian/Alaska Native and Pacific Islander work; those results are not dissimilar from the results in this report.

Methods

Staff used a snowball methodology to contact and interview over 30 people in order to identify individuals who could form small (4-5 person) culturally specific project teams composed of research and practice-based partners. The goal was for those teams to include individuals with lived experience from African American, African Immigrant & Refugee, and Latinx communities and with experience in public health and/or research in these communities. Interviews took place between October 2019 - March 2020.

Two project teams were formed: one for the African American and African Immigrant and Refugee communities and another for the Latinx communities. Project teams were facilitated by the Research Justice Institute at the Coalition of Communities of Color (CCC), whose work focuses on research and data justice and includes nineteen culturally specific community-based organizations, and OHA staff. The teams met five times for two hours each from May 2020 - April 2021 to review data and methodologies, suggest and review additional requested analyses, discuss strengths, gaps and limitations, identify topics for community led data collection, review results of the data collection, and develop recommendations.

The two project teams conducted the bulk of their work separately and came together for the last two meetings to review results of community-led data collection and provide recommendations for the work going forward. The project teams agreed to report their work together in this report because 1) the topic areas of interest/review overlapped significantly (e.g., mental/behavioral health and health care access), and 2) the COVID pandemic limited the capacity for community engagement and there was desire to limit/integrate requests of community groups.

After reviewing the BRFSS and OHT data, project teams decided to focus the community-led data collection on areas they spent the most time reviewing:

1) Mental and behavioral health, especially access to care. These data were gathered through a statewide behavioral health survey of BIPOC communities.
2) Health of youth. Information about this issue came from Madison High School youth, who gave input into the design of OHT questions.

The findings from this community-led data collection effort are integrated throughout the report. The project teams reviewed the protocols for protection of project participants.

Findings

Throughout this engagement process, community partners, including members of the project teams, shared a common concern and perspective: that both survey tools, BRFSS and OHT, reproduced the assumptions, norms, and methodologies of white dominant culture and, in so doing, created further harm by misrepresenting racial and ethnic populations. Project team members' concerns, observations and critiques are organized into six themes discussed in detail below with relevant examples. The themes are bound together by this fundamental perspective. The particular ways that this institutional culture approach produces harms are discussed within each of the six themes:

1. Lack of Meaningful Context
   A consistent critique from project team members across subject areas was that the survey results lacked the necessary context to make the 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. Team members also shared that survey questions

overly focused on individual behavior rather than contextual ones to make sense of how health behaviors/realities are shaped culturally and socially.

2. Intersectionality

   The project teams were adamant that it is essential to recognize that individuals are complex and live and have their identities within multiple overlapping and often politicized and/or socially charged structural conditions -- gender, race, sexuality, nationality, ability status, class, education -- that shape their everyday experiences and their ability to access power, resources, and opportunities. Being able to elucidate intersectionality by analyzing data by multiple demographics is essential for understanding experience and advocating. Minimally, data needs to be able to be disaggregated by race, ethnicity, income, age, primary language, and country of birth.

3. Actionable Data

   Team members insisted that questions need to be worded such that they produce data that accurately leads to direct action meaningful to the community. The data needs to point directly to potential specific policies, programming or practices.

4. Sample Size/Response Rate

   Project team members were very concerned about the low response rate among BIPOC communities. BRFSS telephone survey outreach methods are biased toward older white people. The team strongly recommended that BIPOC community members be involved in question development and administration of the survey to their own community. The lack of representativeness in the data tainted any usefulness of the data.

   Team members insisted that it was important to not let the "small numbers" argument get in the way of sharing data with communities. Sometimes communities see this as intentional, which can create distrust. They recommended providing cautionary narrative with the data, about possible interpretation of small numbers. They strongly urged restraint from creating comparison tables across demographics that forced uniform statistical measure or margins of error that prevent reporting the information.

5. Integration of Other Data Sources

   The project teams requested access to data from other collection systems in an attempt to provide more context for the BRFSS and OHT/SHS data. Specifically, they requested and were provided (1) vaccination data from ALERT IIS and (2) free and reduced lunch data from the Oregon Department of Education. The data were helpful and highlighted the need for integration of data systems across sectors.

   The team also highlighted, though, that all of the data was gathered using dominant culture surveillance systems and that, therefore, each was subject to some of the same limitations. They pointed out that using data from one system

to confirm other dominant culture surveillance data can create an echo chamber effect.

6. Translation and Health Literacy

   Project team members were concerned that Spanish-speaking Oregonians from various Spanish speaking countries and regions might not understand some of the questions due to the translation. Further, they were worried about using formal or complex language. They wanted to uplift the amount of time they spend addressing health literacy by translating documents into "plain language," meaning words used that those with a six-grade reading level may understand. Individuals have different levels of formal education, and this should be considered when translating questions.

   Overall, the survey translations were well received from the project team, but in some instances their review helped refine the question text to better reflect the actual intention of questions. The group suggested an external advisory group specifically for translation.

Lessons, Recommendations & Next Steps

Lessons Learned

Community Engagement is Critical for Scientific Integrity of the Data

This work with community partners has clearly shown that scientific integrity is compromised without community engagement in data collection, analysis, interpretation, dissemination and use. Without community involvement, the validity of the data is questioned and as a result it limits relevancy, generalizability and use of the data collected.

Accountability

Individual behavior occurs within and is influenced by the contexts within which they occur. Understanding the determinants of behavior is impossible without understanding context. Without information about the determinants of behavior, the data are not appropriately actionable and governmental public health agencies cannot be held accountable for population health improvement. Without meaningful actionable data, public health agencies cannot be held accountable for the systems they uphold and the public they serve. The burden of accountability for public health continues to be put on individuals, which is often conflated with entire communities, instead of dominant institutions and organizations that build and maintain the systems.

Building Trust through Equitable Partnership & Data Practices

OHA staff involved with this project learned much about needed practices to help build trust with community partners. These practices helped create and sustain an equitable partnership:

- Recognize and value the unique background, skill sets and expertise of all partners.

- - - Demonstrate the value of the expertise and time of community members by paying them.
    - See community members as experts in what will aid their community to be healthier and happier.
    - Center and value community knowledge.
- Share data and technical assistance about the datasets as needed.
- Share data with small sample size when possible and provide cautionary narrative about possible interpretation of small numbers.
- Share project/survey budgets with community partners.
- Share translated surveys for review.
- Defer human subjects' protections to community research partners.
- Increase collection of contextual/environmental and actionable data.
- Facilitate opportunities for community-led data collection.
- Improve integration and reporting of population health outcome measures with collected contextual information.

Avoid Further Harm

Current practices of public health surveillance are creating harm. Harm is often reproduced unintentionally through practices that have become normalized. Through this project, team members identified some examples of harmful practices and outcomes relating to data that are perpetuated by current practices:

- Individual behavior focused questions, such as the ones in BRFSS and OHT/SHS, presented without the necessary contextual questions, shift the entire responsibility onto the individual and let institutions off the hook for their part in creating, perpetuating and exacerbating disparities. As a result, the data misrepresents people's experiences, further blames and causes them harm. Community participation in survey development, data collection, and data analysis and reporting is essential for avoiding further harm to BIPOC communities.
- Conflating systemic injustices (e.g., racism), with interpersonal experiences (e.g., bullying), prohibits making necessary changes to upstream decisions and allocation of resources that ensure that BIPOC folks have access to the support they need in their schools, neighborhoods, and communities.
- Qualitative questions allow for community voice and stories to be added to the research, unlike quantitative questions that have rigid boundaries for meaning making. Qualitative data can help provide the context necessary to understand, for instance, experiences of medical mistrust and discrimination from the words of those being researched. Lack of context removes an opportunity to better understand community experiences and strategies and deflects attention and resources away from solutions that will increase access to better health.
- The lack of questions in the BRFSS about behavioral health care providers beyond mainstream/Western medical sources, such as traditional health workers, faith leaders, and peer support specialists, deflects attention and resources away from supporting a trained workforce pipeline that can serve BIPOC communities in culturally and linguistically responsive and affirming ways.

- When dominant institutions defer to the community, they have an opportunity to avoid doing unintentional harm. There must be BIPOC community members and leaders at every decision making table. Nothing for community without community is truly for them.

Without intentional and institutionally embedded steps towards course correcting practices we know to be harmful, BIPOC communities will continue to be excluded from the resources, investments, and programs needed for holistic well-being.

Recommendations & Next steps

The findings from this survey modernization project serve as a call to action for OHA to work with communities to develop a clear conceptual framework for its work generally and specifically for population surveys like BRFSS and OHT/SHS in how to sustainably engage community leadership in data modernization. It is also a call for OHA to fund strategy development to build more community capacity and power. Below are specific recommendations from the project teams about steps needed to achieve these goals.

- 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 Health Interview Survey**.
- 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 who are being "researched." Let data project 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**; when there are requests of the data, ask who and how the data will be used.
- 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.
- County Health Rankings and BIPOC data hubs can serve 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 help achieve greater flexibility from federal requirements.

The lessons and recommendations from this survey modernization work with community partners should serve to inform the State Health Improvement Plan (SHIP) specifically development of Social Determinants of Health metrics, OHA Strategic Data Plan, and OHA Accountability Metrics.

BACKGROUND

Oregon Public Health Division has relied on the Behavioral Risk Factor Surveillance system (BRFSS) and Oregon Healthy Teens (OHT) for survey data on adults and youth in the state. The Oregon Healthy Teens survey was Oregon's effort to monitor the health and well-being of adolescents. An anonymous and voluntary research-based survey, OHT was conducted among 8th and 11th graders statewide. The current Student Health Survey (SHS) replaces OHA's two previous youth surveys, the Oregon Healthy Teens Survey (OHT) and the Oregon Student Wellness Survey (SWS). Oregon's Student Health Survey is a collaborative effort with the Oregon Department of Education (ODE) to improve the health and well-being of all Oregon students to help them succeed. The SHS is a comprehensive, school-based, anonymous and voluntary health survey of 6th, 8th and 11th graders. It is a key part of statewide efforts to help local schools and communities ensure that all Oregon youth are healthy and successful learners.

BRFSS, a collaborative project of the Centers for Disease Control and Prevention (CDC) and U.S. states and territories, is the largest, continuously conducted telephone health survey in the world. The objective of the BRFSS is to collect state-specific data on preventive health practices and risk behaviors that are linked to chronic diseases, injuries and preventable infectious diseases in the adult population.

In Oregon, over 8,000 BRFSS telephone surveys are completed each year. BRFSS data are collected from a random sample of adults aged 18 years and older. For the past several years, 80% of Oregon respondents participated through a cell phone sample while 20% participated through a landline sample. In addition to these annual surveys, a BRFSS racial and ethnic oversample has been done every 4-6 years to increase the number of telephone survey respondents from each of the following communities: Black/African American, American Indian/Alaska Native, Asian, and Pacific Islander.

Health departments have become dependent on BRFSS data for a variety of purposes, including targeting services, securing grant funding, addressing emergent health issues, informing proposed legislation, and measuring progress toward public health objectives. Thus, it is imperative for our survey systems to collect data that accurately reflects the lived experience of youth and adults in Oregon.

The BRFSS faces numerous challenges in terms of data quality and sustainability, with some key ones described below in table 1.

Table 1. Major Challenges to BRFSS

Challenges	
Expensive	Annually, the standard Oregon BRFSS costs over $900,000 (over $100 per completed survey); the racial and ethnic oversample is even more expensive, at over $500 per completed survey.
Survey burden	The survey has become too long (average 24 minutes, range: 10-62 minutes). Because BRFSS is the primary source of data on many health indicators, demand has increased to include more questions over time. Longer surveys with no incentives can lead to more people declining participation and more terminating the interview prior to completion. Further, interviewers' rushing to complete a long survey can conflict with culturally responsive practices.
Representativeness	There are increasing challenges with getting people to participate in a phone survey that involves calling people randomly, raising concern about how representative the data are of adults from various communities across Oregon. The survey is also only offered in English and Spanish, further limiting the representativeness of the sample.
Validity	The validity of responses to sensitive questions is unclear given the changing perception of privacy among the general population and variability in cultural norms about privacy.
Lack of community engagement	Communities of color, tribal nations, and other specific communities have not been routinely engaged in BRFSS survey design, analysis, interpretation of results, or dissemination; yet their input is critical for assuring methods are culturally responsive, data are valid, results are useful for communities, and findings are interpreted accurately.
Lack of data on the Pacific Islander community	Too few BRFSS participants are from Pacific Islander communities to calculate reliable indicator estimates, even with the BRFSS racial and ethnic oversample.

PURPOSE OF THE PROJECT

The public health modernization framework was used for identifying an approach to addressing the aforementioned challenges with BRFSS. In addition to the assessment & epidemiology foundational capability, health equity and cultural responsiveness, and community partnership development capabilities are critical in thinking about solutions. The aims of this project were to:

- Elevate community voice in understanding and interpreting BRFSS and OHT survey data
- Identify strengths, gaps and limitations in BRFSS and OHT data

- Facilitate community led data collection on topics of project team interest and from identified gaps in instruments
- Guide and recommend avenues for sustainability and integration of survey modernization components
- Provide community perspective on the usefulness of BRFSS and OHT data
- Provide community perspective on OHT and BRFSS methodologies
- Identify improved data collection methods and recommendations for continued community engagement

To address the lack of community engagement, and concerns about survey representativeness and validity:

The Oregon Legislature's investment in Public Health Modernization for the 2019-2021 biennium includes funding to update the Office of the Public Health Division (OPHD) adult survey system to address these challenges and gather better data for specific communities. OPHD leadership asked Program Design and Evaluation Services (PDES)[1] to lead this project. The Office of the State Public Health Director (OSPHD) directed PDES's work on this project, and the OPHD Science and Epidemiology Council (SEC) provided scientific oversight.

Two complementary approaches were used to identify how to update the system: 1) collaborating with communities and 2) identifying innovative statistical and survey methods from the scientific literature. These two approaches were implemented simultaneously and will inform each other. This report focuses on the work to engage and collaborate directly with the Latinx and Black/African American communities. The second approach of identifying innovative and effective survey methods for increasing representativeness of BRFSS is described in a separate report.

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[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.

We will collaborate with communities to analyze, interpret, and report BRFSS and OHT public health data and to identify improved data collection methods.

We have combined four years of the standard BRFSS and weighted it for communities of color, instead of doing the usual, very expensive, phone-based BRFSS racial and ethnic oversample. In this four-year aggregate BRFSS file, there are sufficient numbers of survey participants within the Latinx, Black/African American, American Indian/Alaska Native, and Asian communities for analysis. The money saved is being used to help fund communities to collaborate with us in the analysis, interpretation, and reporting of the data, and to identify improved data collection methods and recommendations for continued community engagement, as described below.

The following methods were used to address the lack of community engagement and concerns about survey representativeness and validity.

METHODS

OHA collaborated with and funded the Coalition of Communities of Color (CCC) and community-specific data project teams for the Latinx and Black/African American communities. Drs. Andres Lopez and Mira Mohsini were project partners from CCC. Dr. Kusuma Madamala, Tim Holbert and Tom Peterson were the OHA project partners. This CCC & OHA internal team met weekly for the project period.

OHA staff used snowball methods to contact, interview and recruit researchers and advocates from communities to form small (4-5 person) culturally specific data project teams.

This project was initiated under the mistaken assumption that staff could engage existing OHA community partnerships in finding project team members. Staff quickly found that while partnerships with community organizations existed within OHA programs, they were siloed and not coordinated organization-wide, which made them effectively inaccessible.

Given the inchoate state of a formal partnership network to help with finding potential project team members, staff undertook recruitment themselves. This required unexpected use of limited resources to initiate the project. Project staff used a snowball methodology to develop a list of potential members for two small (4-5 people) culturally specific analytic project teams – a LatinX team and an African American/African Immigrant & Refugee team. Between October 2019- March 2020 project staff talked with professional contacts within community organizations, Multnomah County Health Department, the Office of Equity and Inclusion, current OHA community partners including the Coalition of Communities of Color – our survey modernization project partner, and reviewed past state-wide internal and external community health data reports, and the Health Equity Researchers of Oregon (HERO) list to identify people with lived experience and experience in public health and/or research.

The snowball methodology resulted in approximately 30 interviews that were conducted with individuals identifying with the African American, African Immigrant, African Refugee or LatinX communities. These interviews ranged from 30 minutes to one hour in length. In person meetings were held when possible. A high-level project overview was emailed to participants ahead of the meeting. The purpose of the work was reviewed together as well as a draft process for the project activities. Questions were asked of participants to solicit their thoughts and recommendations for process improvement for the different activities. Interview participants were also asked for their recommendations for other individuals and/or organizations to interview in each respective community. Individuals who were both interested and available were asked to be part of these small data project teams.

Many lessons on community engagement were learned in the process of recruitment. While these are discussed in a separate report ("Survey Modernization - Lessons Learned from Partnership Development"), it is worth reiterating here that staff learned that (1) the work of engaging, building trust and sustaining community partnerships requires time – at least 2-3 times longer than anticipated or budgeted for; (2) community partners want transparency and honesty in budgets, project goals and dissemination of results; (3) community members were very concerned about the short time-frame of the project, data ownership, and how the analyses were going to be used, and what real positive benefit the project would have for their community; (4) while there was great interest in the project, lack of trust in government, lack of time and lack of "band-width" were all barriers to participation; (5) contracting and insurance requirements were another hurdle that had to be overcome to successfully engage community members.

The project teams used community-identified priorities to guide analyses of both the 4-year aggregate BRFSS file and Oregon's school-based survey data of youth - 2019 Oregon Healthy Teens Survey (OHT)[2], and interpretation of those results. These partners then led community-driven data collection on topic(s) and methods of their choice. A starting place for these community collaborations was with the Latinx, Black/African American and tribal nations, with the hope that they can serve as a model for collaborations with other specific communities and/or topical areas in the future.

Data Project Team Process

Project team members reviewed the survey instruments, advised analyses to be conducted of BRFSS and OHT data, interpreted results (e.g., what resonates and what doesn't, identify limitations, etc.), identified knowledge gaps in the data and suggested areas for community led data collection. Under CCC guidance, team members helped with designing community-led data collection, analysis and interpretation of those results. The project team guided the plans for summarizing results of all analysis and

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[2] The Oregon Healthy Teens Survey is school-based survey of youth. For more information, see https://www.oregon.gov/oha/PH/BirthDeathCertificates/Surveys/OregonHealthyTeens/Pages/index.aspx.

helped summarize lessons learned and recommendations for future engagement in BRFSS and Student Health Survey (note: OHT phase out and SHS going forward). Generally, both teams had greater interest and spent more time reviewing and requesting further analysis of the youth data. Project team members are noted below. Tables 2 and 3 are the topical areas selected for review by each project team. Additional details on project team data review process and meetings can be found in Appendix #1.

Latinx Project Team members

Dr. Lorraine Escribano, Director of Evaluation, Latino Network
Roberto Gamboa, Operations Manager, Euvalcree
Dr. Daniel Lopez-Cevallos, Associate Professor, Oregon State University
Claudia Montano, Projects Manager, The Next Door, Inc
Karla Rodriquez, Community Health Worker, Oregon Latino Health Coalition

Black/African American Project Team members

Dr. Roberta Hunte, Assistant Professor, Portland State University
Oluchi Onyima, formerly of Urban League, now independent consultant
Sherly Paul, Community Health Nurse, Multnomah County Healthy Birth Initiative
Dr. Ryan Petteway, Assistant Professor, OHSU-PSU School of Public Health

Table 2. Latinx Project Team Selected Data Reviewed

BRFSS	OHT 8th & 11th grade
Health Care Access	Mental Health Profile
Chronic Health Conditions	Food insecurity
Health Care Access & any Chronic Health Condition	Sexual health
Influenza immunization	Sexual violence
Substance use	Substance use

Table 3. Black/African American Project Team Selected Data Reviewed

BRFSS	OHT 8th & 11th grade
Health Care Access	Mental Health Profile
Food insecurity	School absenteeism
ACEs by age	Physical activity
General mental and physical health	Sexual health

While the Latinx and Black/African American project teams conducted the bulk of their work separately, they came together for the last two meetings to share findings. The work of these two project teams is shared together in this report because 1) there were overlapping topical areas of data interest/review (e.g., health care access, food insecurity, sexual health), 2) community engagement during COVID meant limiting and integrating multiple requests of community groups, and 3) the project teams agreed that it was appropriate to report the findings together.

FINDINGS

Throughout this process of engaging with community partners, including members of the project teams, a common and widely shared concern was that both survey tools, BRFSS and OHT, reproduced the assumptions, norms, and methodologies of white dominant culture and in so doing, created further harm by misrepresenting racial and ethnic populations. These include:

- Asking questions that focus on individual experiences and behaviors rather than the context that informs certain experiences and behaviors
- No community input into the construction of the survey instruments
- No community engagement to ensure the surveys are being disseminated in culturally and linguistically appropriate ways
- No community engagement into the analysis and interpretation of collected data
- Prioritizing statistical validity that serves to misrepresent and erase the experiences of smaller racialized and ethnic populations and centers the dominant experiences of white populations and causes further harm

Many of these concerns were expressed during the review of BRFSS and OHT data when project teams explored: (1) types of questions asked, (2) question wording, (3) whether data resonated with their experience and local data, (4) concerns about the sample, (5) whether additional information is needed to understand the findings and provide important context that BRFSS and OHT lack, and (6) additional data sources relevant to the BRFSS and OHT data.

After reviewing the BRFSS and OHT data, project teams decided to focus the community led data collection on areas they spent the most time reviewing: 1) mental and behavioral health and 2) health of youth. Because of limitations imposed by the COVID pandemic on community engagement efforts, CCC and project team members from both the Latinx and Black/African American projects recommended integrating community-led data collection with existing community engagement efforts. See Appendix #2 for further information on the community led data collection methods.

Project team members' concerns, observations and critiques are organized into six themes discussed in detail below with relevant examples. The themes are bound together under one fundamental perspective – that the BRFSS and OHT are both products of a dominant institutional culture that centers Whiteness and that this actually harms communities through misrepresentation and blame. The particular ways that this

institutional culture approach produces harms are discussed within each of the six themes. The six themes are:

1. Lack of meaningful context
2. Intersectionality
3. Actionable data
4. Sample size/response rate
5. Integration of other data sources
6. Translation and Health Literacy

Though the themes are highly interrelated, each deserves to be highlighted in its own right as a lens through which we view the work of survey modernization and community engagement. Immediately following the themes are examples, when applicable, of how community-led data collection addressed the issue of concern.

Lack of Meaningful Context

Survey questions focused on individual behavior without environmental context. This practice shifts the entire responsibility of outcomes to the individual allowing institutions to deflect responsibility for the underlying environmental conditions and for their role in the history and current practice of creating, perpetuating and exacerbating disparities. This context is key to detailing cultural and social barriers. Team members expressed that the BRFSS and OHT instruments were asking questions that required further questions for contextualizing data findings.

Health care access

Both data project teams noted that BRFSS health care access questions need to include what's keeping individuals from going to the doctor apart from cost and coverage. Examples noted from project teams included:

- Availability of service?
- Do you know how to use health care coverage?
- Do you know what you are covered for?
- Do you know OHP exists and is free? (assumptions do not qualify because of immigration status)
- Experiences of health care discrimination & medical mistrust?
- Do you feel involved in decisions about your healthcare?
- Do you feel listened to by your provider?
- Do you feel safe using healthcare services?
- Use of health consultants, naturopathic or spiritual healers?

The statewide behavioral health survey, a community led effort that was disseminated widely among Black/African American and Latinx communities, included several questions about health care access and, in particular, asked respondents about what conditions prevented them from seeking care. Table 4 below compares the BRFSS questions and the community led state-wide behavioral health survey question about health care access.

Table 4. BRFSS questions versus community led questions about health care access

BRFSS – Health care access	Community led Data Collection – Health care access
1. Do you have **any kind of health care coverage**, including health insurance, prepaid plans such as HMOs, government plans such as Medicare or Indian Health Services? 2. Are you **currently enrolled in the Oregon Health Plan (OHP)**, which is the State's Medicaid program? 3. Do you have one person who you think of as your **personal doctor or health care provider**? 4. Was there a time in the past 12 months when you needed to see a doctor but could not because of the **cost**? 5. About _how long has it been_ since you last visited a doctor for a routine checkup?	Do any of the following **prevent** you or members of your family from seeking support from your Coordinated Care Organization (CCO) or other health provider with issues around stress, frustration, worry, anger, addiction, violence, and/or abuse? Please select all that apply. ☐ CCO/health **provider is too far away** ☐ Don't have access to **transportation** ☐ Don't have access to **childcare** ☐ Don't have consistent access to **internet** for virtual appointments ☐ Don't have **health insurance** ☐ **Process for making an appointment** with a provider is difficult ☐ **Don't feel safe** visiting my provider ☐ **Provider cannot communicate in a language** that I'm comfortable using ☐ Provider doesn't have the same **cultural background** as me ☐ The **service(s) I/we need is not covered** by my insurance ☐ The **service(s) I/we need is not available** near me ☐ **Not aware of what services are available** near me ☐ Information about services is not provided in a **language** that I'm comfortable using ☐ **Don't trust that my CCO/health provider will be respectful of my cultural values**

Experiences of discrimination/harassment

Both teams expressed concerns about how discrimination is either not addressed or inappropriately addressed in either BRFSS or OHT. The following examples from the community led data collection highlight the experience with health providers and medical mistrust -- critical missing pieces to understanding barriers to healthcare access.

The community led statewide behavioral health survey included quantitative and qualitative questions that aim to better understand the experiences and conditions of

discrimination that many BIPOC patients encounter. Respondents were asked a series of scale-based quantitative/closed-ended questions. These questions included:

- When you visit a provider, to what extent do you feel that they listen to your concerns?
- When you visit a provider, to what extent do you feel that they understand your concerns?
- When you visit a provider, to what extent do you feel that your concerns are affirmed and validated?
- When you visit a provider, to what extent do you feel that they provide you with enough information to make decisions, experience less worry, and feel safe?

The findings from these questions are below in Figure 1.

Figure 1. Feeling heard, understood, affirmed and informed by health providers
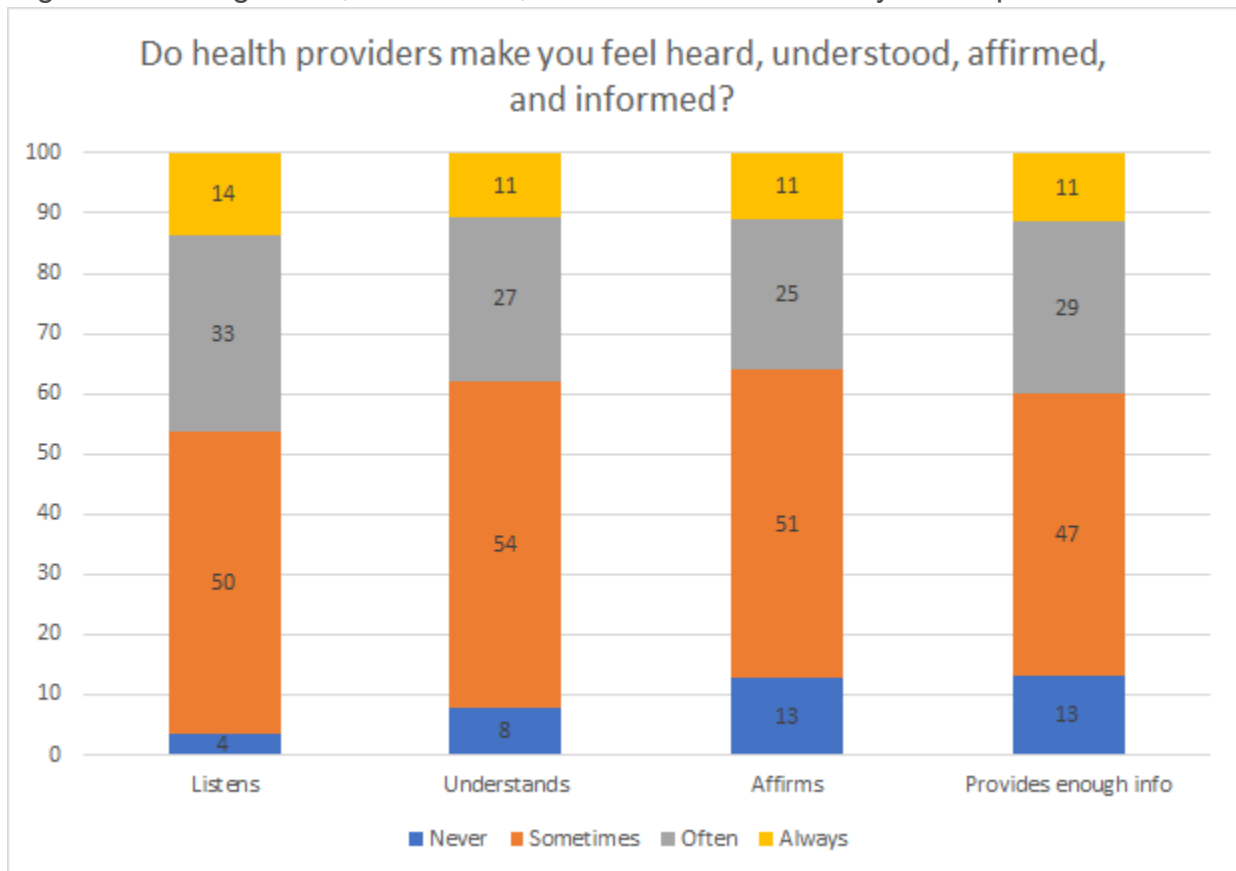

Figure 1. demonstrates that 53-64% of respondents never or only sometimes feel heard, understood, affirmed and informed when seeing a health provider. These data point to bucket areas that require further investigation. What is it about one's visit with a health provider that folks do not feel heard, understood, affirmed, and informed? Answers to these questions provide better contextual and actionable data to support the health of Oregonians. A qualitative/open-ended question about experiences of medical mistrust was also asked on the survey. The question was: In what ways have you, your

family, or community experienced healthcare providers as untrustworthy? The responses were qualitatively analyzed using, first, an open-ended coding strategy and then developing overarching themes from these codes. The results of this analysis are in Figure 2 below.

Figure 2. Experience of medical mistrust

Top themes	Examples
Providers lack empathy	- Dismissive - Patient feels unheard - Disrespectful - Rushed appointments
Experiences of harmful care practices	- Denied care - Misdiagnosis - Unnecessary treatment - Need to self-advocate
Stereotyping by providers	- Presumed incompetent - Assumed drug addiction

Figure 2 provides a view into the contexts and possible action steps required to support the health of Oregonians. Asking qualitative questions to community members invites them to provide details that are essential to monitoring health and providing intervention to systemic inequities. For example, these data provide examples about what the community experiences in terms of the "lack of empathy" or "harmful care practices." Some of the changes that are needed may be interpersonal like a more culturally and linguistically specific bedside manner or it may be organizational like eliminating rushed appointments as common practice. The more qualitative data available, the better equipped decision makers will be to shift harmful systems.

For OHT, project teams asked why discrimination and harassment are only asked in the school setting for both racial discrimination and discrimination based on sexuality and gender. It's not only bias in/during school that affects health. Experience of bias in community, on the way to school, and in daily life can shape stress, focus, amount of physical activity, sleep routines, etc. One team member wondered why not use the validated Everyday Discrimination Scale. There is also a need for in-school/school-related specificity for experience of racial discrimination/harassment – is it from teachers, staff, students, bus drivers, coaches, school resource officers, etc.? What is the discrimination attached to - such as food, school attendance, language, and bullying?

Furthermore, inclusion of racial discrimination as simply a form of "bullying" is problematic. This minimizes the extent/depth of interpersonal racism as connected to/enabled by institutional racism. A team member noted we should not lump forms of systemic devaluation, exclusion, and oppression with getting bullied because of clothes, etc. Actions that are biased, hostile, or violent toward others based on race are racist,

and appropriately viewed as hate speech/actions. Subsuming them under the concept of "bullying" clouds the dynamics of power that are at play.

Team members noted these experiences need to serve as a reminder of the need for systemic, institutional, and organizational change. It is not the responsibility of the person/community to "cope", but for the environment (policies, practices, providers) to become welcoming, inclusive, and anti-racist.

Questions need to be trauma-informed

Like ACEs, the Black/African American team noted how Positive Youth Development (PYD) questions are not useful and damaging for the African American community and developed with a white middle-class population in mind, ignoring racism and focusing on individuals, not systems. The team noted the questions need to be developed with a trauma-informed lens, be conceptually related, dig deeper into causes, and co-constructed with youth.

It can be very traumatizing for youth to read questions that can lead them to feel like the blame is on them. How can you get information that is actionable and doesn't place the focus on the individual? Another concern was that the PYD questions need to be conceptually related. How meaningful and for whom is it to have questions about physical activity in the same index with questions about whether you have a trusted/supportive adult at school? Further, team members noted some related items do not tell us much. While increased exercise is associated with better health, many 11th graders who exercise reported poor health. What other types of questions do we need to ask to dig deeper? Relying on students can get us to those questions. The group recommended asking youth questions like how they felt about themselves and their own development. What questions would they ask of themselves? How would they frame it? An underlying concern was recognizing that students are able to understand and articulate their experiences and trusting them. Table 5 below provides examples from the community led data collection of what youth would ask themselves about their own development.

Table 5. Positive Youth Development – What would youth ask themselves?

Themes	Examples
Gain a fuller understanding of teens' context both in and outside of school	- What activities do you do outside of school? - Do you feel like you have the information to know how to fix your issues? - What are some factors in your life that may disrupt your ability to do best in school? - Do you ever talk to people about what kind of support you need to achieve your goals? - Do you live in a safe environment?
More specific questions about mental health	How do you cope with all the different expectations on your plate?

Themes	Examples
What is going well currently and future goals	- How do you think you can stay strong throughout the year? - Are you feeling stressed out about something? If so, who can help you feel better?
What is going well currently and future goals	- What is currently going good for you? - Do you have goals or plans for your future?

Gender and sexuality questions are hetero- and cis-focused

Youth are more tapped into the connections between mental and sexual health, gender diversity, and sexualities than many adults. Yet, OHT and BRFSS surveys do not allow for much understanding in these areas. Some areas of concern included STI prevention, healthy relationships and sexuality, and power in relationships. The most considerable problem was that these areas needed to cover non-heterosexual relationships. In addition, OHT questions are very condom focused and don't assess other contraceptive methods as thoroughly. Project team members felt the need for more questions about healthy relationships and whether appropriate support, programming, and resources are available at the school. How can we ask actionable questions around sexuality and power, instead of just knowing how many youth experienced sexual coercion? What about that environment or lack of support bolster or limit these experiences? The group also mentioned that it would be helpful to have gender and sexuality questions with a slider option, allowing students to choose along a gradient.

Intersectionality

It is essential to recognize that individuals exist within overlapping structural conditions -- gender, race, nationality, ability status, class -- that shape their everyday experiences and their ability to access power, resources, and opportunities. The project teams were adamant that being able to elucidate intersectionality by analyzing data by multiple demographics is essential for understanding experience and for advocacy purposes. Minimally, data needs to be able to be disaggregated by race, ethnicity, income, age, primary language and country of birth.

For example, age, country of birth and language can be important proxies for the differing experiences of racialization that occur in the context of the United States. The project teams reported that the process of racialization takes a generation. The first generation immigrants don't see the difficulties they encounter when interfacing with institutions as the result of discriminatory practices. The second generation is more likely to accurately ascribe those systematic challenges to institutional racism. One of the critical BRFSS variables that the Latinx team reviewed was the language in which the survey was administered—to help distinguish the differences between the U.S. born versus foreign born Latinx. Research has shown that these two populations have

varying experiences, and it would be more helpful to understand these differences in the data in order to be actionable. A few areas for understanding the differences between these two groups would be useful include: cultural, medical mistrust issues, beyond language barriers, data that support services/programs developed for foreign-born, beyond just focusing on language, differences and similarities for those who are foreign-born but came to the U.S. at an early age.

Actionable Data

Both teams were consistent in their critique that BRFSS and OHT survey questions needed to be written to make the data collected actionable, by which they meant that it needs to be able to directly drive policy and practice. Members reiterated how "surveys are heavily individual behavior outcome focused," and we "need more systemic focus." Further, one team member said, "We don't need more detailed data about how Black folks experience even worse ACEs - more toxic environments -- we already know that. We need data that can help drive policy."

Consistently, throughout the process, the project teams reiterated that for data to be meaningfully actionable, they need to yield accurate insights about the systems (infrastructure, neighborhood, family life, racism, transportation, etc.) in which people are making the choices they best can. They kept emphasizing that the surveys overly focus on individual behavior while ignoring the systems in which the behaviors occur which has the effect of (1) blaming the person and further damaging communities and (2) missing the potential points of policy and practice that could be changed to support people. The effect is to misunderstand that behaviors are not based on choice in sub-optimal environments created by systemic oppression and historical racism and focusing on how individuals need to change their behaviors without addressing how to improve the systems in which those behaviors take place, is to further blame and traumatize communities.

School absenteeism

For OHT, both teams noted the questions only focus on school and not the everyday lives that impact how, when, and why students show up at school. As an example, teams questioned why students are missing school beyond physical and emotional and mental health reasons. Are they working a job? Is there a hostile school climate? Are they caring for a family member? How is food insecurity affecting attendance? A similar set of questions apply to sleep as well - is a student getting less sleep because of a job they have to work, stress, or familial obligations?

Table 6. School Absence

Oregon Healthy Teens	Community led Data Collection – What would youth ask about school absence?
During the past 12 months, how many days of school did you miss – • for any reasons? • because of physical health reasons? • because of emotional or mental health reasons? How many days of school did you have unexcused absences (meaning you skipped or cut school)? Did you miss one or more hours of school due to any of the following reasons? • I had a toothache or painful tooth; • My mouth was hurting; • I had to go to the dentist because of tooth or mouth pain; • I had to go to the hospital emergency room because of tooth or mouth pain; • I had a mouth injury from playing sports	• Just ask them "What's causing you to miss school?" (open ended) • Do you have problems at home/outside of school? • Are you doing ok? • After each question just add a "why section" • What is elevated above school? Why does it come up? • Do you have other things to do other than school? • What are things affecting you outside of school that keep you from being successful? • In what ways does school feel unsafe to you? • Is someone making fun of you or are there stressful conditions you want to avoid at school like students or teachers? • What would make school a safer environment? • What at schools feels welcoming/accepting? What does not?

Knowing the broader circumstances around school absence (e.g., work, care for a relative, etc.) can lead to developing local programs or policies to improve attendance and support students in holistic ways. If these circumstances are not questioned, then action can't be taken to address school absenteeism.

Physical activity

The teams expressed the need for a broader understanding that safety is connected to health and that the physical activity question itself is not actionable. The teams noted it would be helpful to better understand safety from the perspective of community and physical environment. Are neighborhoods safe for folks to get exercise? Can folks afford gyms, or do they feel like welcoming spaces? They noted very little sidewalks/shoulders on the road in rural areas, so it may be hard to go for a walk.

Table 7. BRFSS Physical Activity

| BRFSS 2015-2018 Combined File Physical Activity Question	What is needed to be actionable?
During the past month, other than your regular job, did you participate in any physical activities or exercises such as running, calisthenics, golf, gardening, or walking for exercise?	Understanding of what's preventing them from being physically active Mapped in relation to policy-related physical activity contexts. Examples: ● Joint use agreements between schools and public ● Amount of greenspace ● % of jurisdiction zoned for public recreation use ● Density of free gym facilities as ratio of non-free ones ● Traffic/pedestrian injury rates ● Sidewalk existence & quality ● % of tax revenue invested in parks This then renders PA responses open to deep examination and action, e.g., What is the relationship between joint use agreements and PA rates for xyz county/neighborhood? Is there a demographically comparable area w/ similar level of agreements that has lower PA rates? Why?

As noted by one project team member, "Behaviors evolve/match contexts. Policy creates/shapes/maintains contexts. This is not news to any of us. How come our surveys appear impervious?"

Use of health care interpreters & Traditional Health Workers

Access to health care questions in BRFSS also don't ask what would facilitate individuals seeking care. Community led data collection found that Traditional Health Workers (TWH)[3] are utilized ("sometimes," "often," or "always") over double the rate that healthcare interpreters (Figure 3). When these types of questions are not asked, further action cannot be taken to increase access. If data collected demonstrate that TWHs are utilized more frequently than health care interpreters this can help take actionable steps to train and hire more THW and peer support specialists who can: (1) provide culturally responsive care and (2) help people navigate health systems.

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[3] These are people who are trained by the Oregon Health Authority to provide health care services to their communities, including help with childbirth (Doula) and mental and behavioral health support (Peer Support Specialist).

Figure 3. Asking Actionable Questions -- A Case for Training & Hiring More Traditional Health Workers
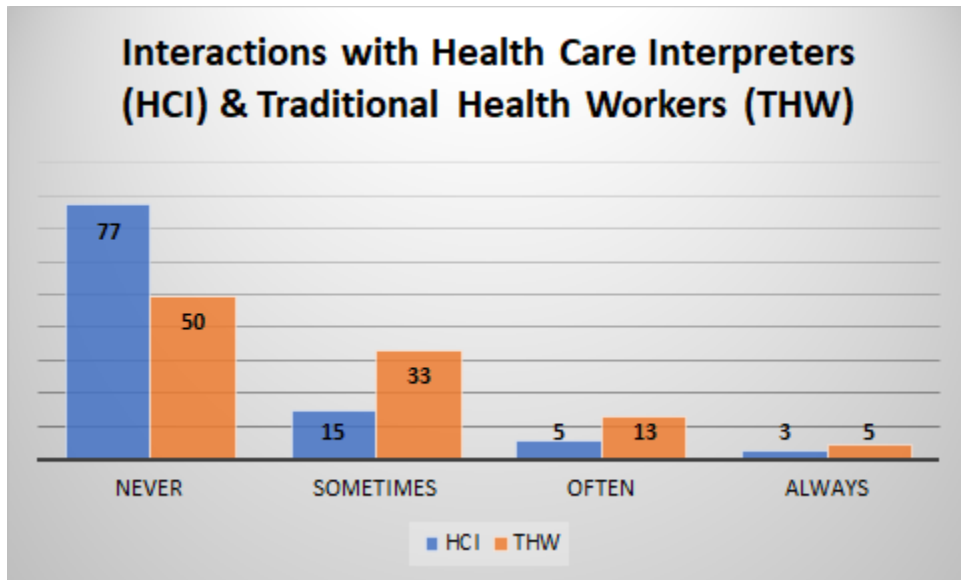
Sample Size/Response Rate

Team members were generally concerned with the low number of Black respondents, practically across the different geographies in Oregon. They suggested more Black community members participate in the question development and administer the survey to other Black people. Due to the low sample size, team members questioned if the data make sense to the broader community or only descriptive of those who responded. They question its representativeness and therefore usefulness of the data.

Integration of Other Data Sources

Influenza immunization

Latinx team requested and reviewed the BRFSS influenza vaccination data in July 2020 and noted that Latinx respondents were the least likely to report having received influenza vaccination. The Latinx team didn't believe this was due to some cultural values that were anti-immunization/vaccines, but because of social barriers around access to health insurance and the cost of immunizations. They wanted contextual data to help them make sense of the self report BRFSS results. Some team members thought these numbers made sense, others thought they were low due to their years of work trying to enroll more Latinx folks into OHP, for example.

Free and reduced lunch

Team members questioned how accurate it is to ask students if they participate in free and reduced lunch programs. They noted that students may not know or want to share this information. In addition, in some areas the entire school population qualifies for free and reduced lunch, but parents are still asked at the beginning of the year. The Latinx team wanted to compare ODE data and OHT. ODE Free and Reduced lunch data by ethnicity was found and shared with team members. For OHT 2019 – Hispanic/Latino respondents "Do you receive free or reduced priced lunches at school?" 8th grade – 57% and 11th grade – 61%. In comparison, ODE reported approximately 75% of all Hispanic students from their Fall 2019-2020 data enrolled in free and reduced lunch.

The teams also noted that the integration of these data sources should not be viewed as validating self-report data since those data sources are also collected by government agencies and may not accurately reflect community needs.

Policy related contexts

As noted in the physical activity example, there is a more systematic need for mapping health behavior data to policy related contexts that can impact behavior. State and local public health workforce needs to integrate legal epidemiologists who study and deploy law as a factor in the cause, distribution, and prevention of disease and injury in a population. This skill set is necessary to better understand environmental contexts to health behavior and can help drive policy towards population health improvement.

Translation and Health Literacy

Numerous Latinx team members were curious about the translation of the questions in Spanish. They were concerned that Spanish-speaking Oregonians from various Spanish speaking countries and regions might not understand some of the questions due to the translation. Further, they were worried about using formal or complex language. They wanted to uplift the amount of time they spend to translate documents into "plain language," meaning words used that those with a six-grade reading level may understand. Individuals have different levels of formal education, and this should be considered when translating questions. How do we make it easier for people? How do we make sure we are using health terms and questions that are translatable in plain language? If we use terms like Latinx, how do we contextualize that language? Some older Latinos may not understand it, so how can we be more inclusive? The Latinx team reviewed the translated BRFSS and translations methods. Overall, the survey translations were well received from the project team, but in some instances their review helped refine the question text to better reflect the actual intention of questions. The group suggested an external advisory group specifically for translation. Advisory members should come from the community, so they not only know the language but the cultural context in which the language is used or not. Validity of the survey instrument may increase from review of a translation advisory group.

Ensuring that surveys are translated in accessible ways leads to far more representative and reliable findings. The community led behavioral health survey, which was co-constructed with BIPOC community members and available in English and Spanish, demonstrates the value of including accessible language. The questions intentionally did not use the terms "mental health" or "behavioral health" and instead used everyday descriptors such as stress, frustration, worry, addiction and their Spanish translations. Table 8 is an example of a question in English and Spanish about ease of accessing culturally and linguistically response services followed by the findings according to each language survey.

Table 8. English and Spanish questions included in the community led behavioral health survey

How easily can you access support for issues around stress, frustration, worry, anger, addiction, violence, and/or abuse from providers who understand your **cultural background**?	¿Con qué facilidad puede acceder al apoyo para problemas relacionados con el estrés, la frustración, la preocupación, la ira, la adicción, la violencia y / o el abuso de proveedores que comprenden su **origen cultural**?
How easily can you access support for issues around stress, frustration, worry, anger, addiction, violence, and/or abuse from providers who **speak your language**?	¿Con qué facilidad puede acceder al apoyo para problemas relacionados con el estrés, la frustración, la preocupación, la ira, la adicción, la violencia y / o el abuso de proveedores que **hablan su idioma**?

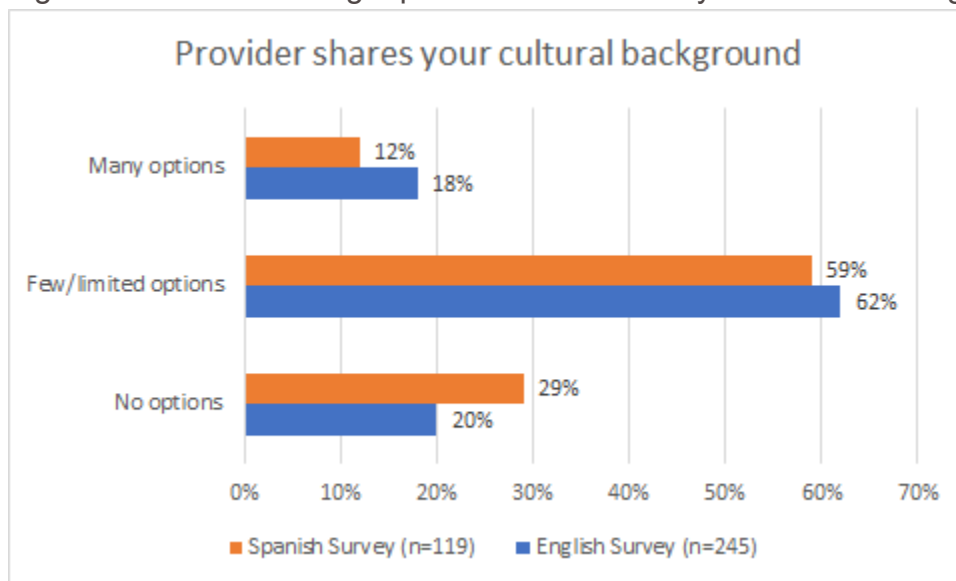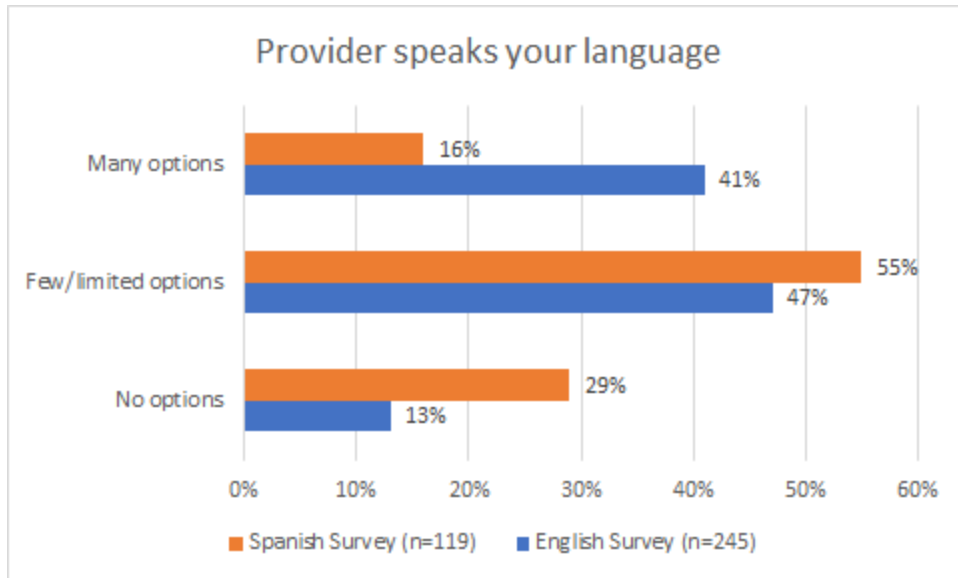Figure 4. Ease of finding a provider who shares your cultural background

Figure 5. Ease of finding a provider who speaks your language

Provider speaks your language

	Spanish Survey (n=119)	English Survey (n=245)
Many options	16%	41%
Few/limited options	55%	47%
No options	29%	13%

LESSONS LEARNED & RECOMMENDATIONS

This work with community partners has clearly shown that scientific integrity is compromised without community engagement in BRFSS and OHT survey data collection, analysis, interpretation, dissemination and use. Validity is questioned and as a result it limits relevancy, generalizability and use of the data collected. Behavior questions presented without context shift entire responsibility to the individual and let institutions off the hook for their part in creating, perpetuating and exacerbating disparities. As a result, the data misrepresents people's experiences, further blames and causes them harm. If the data are not actionable, then governmental public health can't hold itself accountable. Governmental public health is accountable to the communities it serves and data from BRFSS and OHT in their current form prevent our ability to do so.

Lessons Learned

Equitable data practices

Below are lessons learned in collaborating with community leaders and members on this project about how to build trust by sharing resources, power and being transparent.

- Recognize skill sets, background and respect of each community & government partner are valued
- Respect community members by paying them for their time and expertise
- See community members as experts in their areas – center & value community knowledge
- Share data and TA as needed – in this case BRFSS & OHT Datasets, requested contextual data (i.e. ALERT IIS & ODE) & BRFSS pilot results

- Resist letting the "small numbers" argument get in the way of sharing data with communities. Sometimes communities see this as intentional and can further distrust.
- Share project/survey budgets with community partners
- Share translated surveys for review
- Defer human subjects protections to community research partners
- Increase collection of contextual/environmental & actionable measures collected by both Community led data collection and State BRFSS and SHS
- Improve integration and reporting population health outcome measures with collected contextual information
- Those measures should be considered for inclusion in the Healthier Together Oregon State Health Improvement Plan metrics

Avoiding further harm

Ensuring that data collection efforts accurately represent the experiences of communities of color by asking contextual questions is critical. The fact that the types of questions asked in the BRFSS and OHT/SHS fall short of providing important contextual details is fairly well known. This survey modernization process has demonstrated that (1) asking more relevant and context-specific questions cannot be done without the participation of community members and without deferring to their knowledge and lived experiences, and (2) community participation in survey development, data collection, and data analysis and reporting is critical for avoiding further harm to BIPOC communities.

Harm is often reproduced unintentionally through practices that have become normalized. Some examples harmful practices and outcomes relating to data collected via the BRFSS and OHT/SHS include:

- Conflating systemic injustices, like racism, with interpersonal experiences, as elaborated in the discussion above about the OHT bullying questions. This conflation prohibits making necessary changes to upstream decisions and allocation of resources that ensure that students of color have access to the support they need in their schools and communities.
- The lack of or under-utilization of qualitative questions to understand, for instance, experiences of medical mistrust and discrimination deflects attention and resources away from solutions that will increase access to health care providers.
- The lack of questions in the BRFSS about behavioral health care providers beyond mainstream/Western medical sources, such as traditional health workers, faith leaders, and peer support specialists, deflects attention and resources away from supporting a trained workforce pipeline that can serve BIPOC communities in culturally and linguistically responsive and affirming ways.

Without intentional and institutionally embedded steps towards course correcting practices we know to be harmful, BIPOC communities will continue to be excluded from the resources, investments, and programs needed for holistic well-being.

Project Team Recommendations & Next Steps

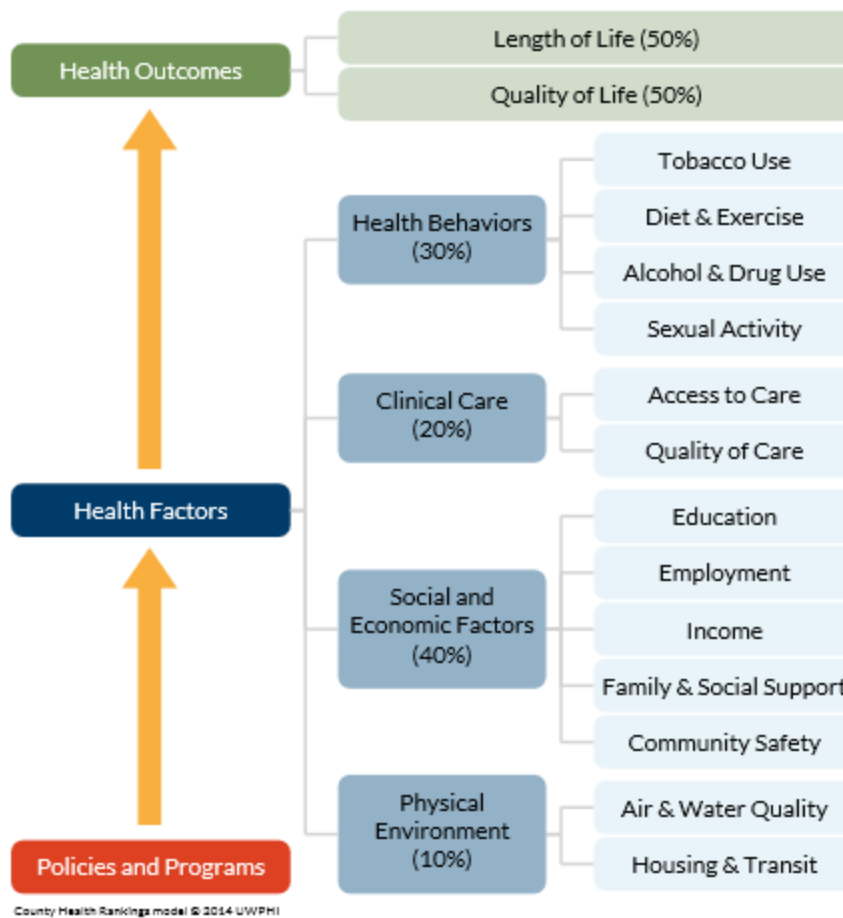Below are specific recommendations suggested by the project teams as well as possible next steps.

- 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**
- Facilitate the use and application of community led data collection by OHA
- Conduct a **minimal BRFSS** – explore lessons from the **CA Health Interview Survey**
- Integrate **Community Leadership** in survey development, administration, analysis & use. As an example, de-center programmatic outcomes/needs by bringing more BIPOC folks who understand how data is used for policy to be part of the survey development.
- Establish a Survey **Translation Advisory Committee**
- Continue **data project teams** and ensure team members are made up of folks who share experiences of those who are being "researched"
- Include **both quantitative and qualitative data** that can contrast and provide more depth to what "the numbers" are telling us
- Engage **Community Based Organizations and/or Regional Health Equity Coalitions** in survey administration
- Re-engage the Health Equity Researchers of Oregon (HERO) group
- Call upon **OHA as a grant recipient to advocate for changes** in the national framework for BRFSS and other national health survey administration to help achieve greater flexibility from federal requirements.

This survey modernization work with partners serves as a **call to action & funding of strategy development** of what the work can look like and who should be engaged. How can state and local governmental public health build more community capacity and power through BRFSS and SHS health data collection systems? How can the state and communities collaborate to create sustained integration of community leadership in survey modernization?

A part of that call to action is a need for a clear conceptual framework guiding OHA in general, and BRFSS/OHT more specifically, that spells out the multilevel, multilayered understanding of the issues. At a minimum, this conceptualization provides more transparency about what is being measured (and hopefully why) and acknowledges the biases and limitations in their approach(es).

The County Health Rankings was one conceptual framework provided.

Figure 6. County Health Rankings Model

Health Outcomes
- Length of Life (50%)
- Quality of Life (50%)

Health Factors

Health Behaviors (30%)
- Tobacco Use
- Diet & Exercise
- Alcohol & Drug Use
- Sexual Activity

Clinical Care (20%)
- Access to Care
- Quality of Care

Social and Economic Factors (40%)
- Education
- Employment
- Income
- Family & Social Support
- Community Safety

Physical Environment (10%)
- Air & Water Quality
- Housing & Transit

Policies and Programs

County Health Rankings model © 2014 UWPHI

Project teams also shared a working model for Community Data Hubs in Figure 7 below where OHA directly funds local public health agencies and/or Community BIPOC data hubs. The dotted line connects the data hubs with the assumption being collaborative working processes to share and learn from each other occurs and perhaps is mediated by a data coalition/consortium. Data sharing and technical assistance occurs between and the data hubs, LPHAs and OHA. Guaranteeing resources for this exploratory work via legislation would help ensure it's not vulnerable to leadership turnover, politics, etc. Continued co-creation of this model or similar models can be another next step.

Figure 7. Preliminary BIPOC Community Data Hub Model
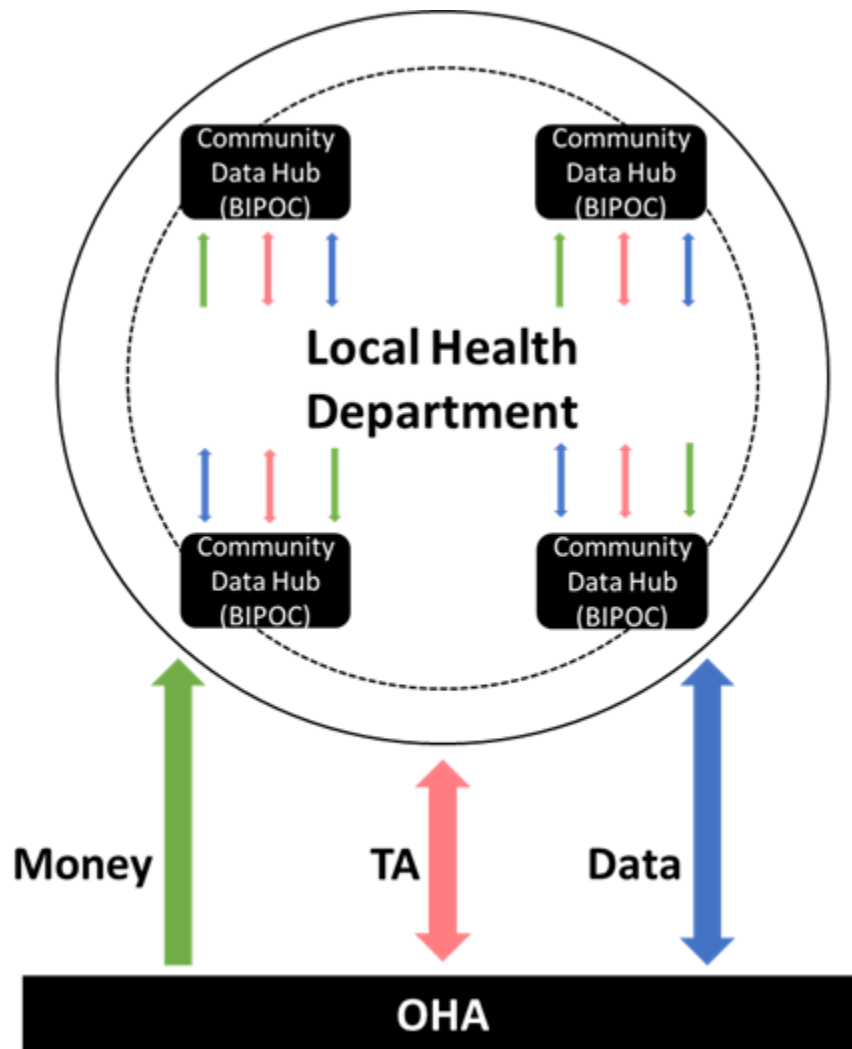
SUMMARY

The public health system in Oregon is not doing enough to develop and sustain community partnerships to address cultural responsiveness and health equity. The 2016 Oregon Public Health Modernization assessment demonstrated limited implementation of the foundational capabilities of Health Equity & Cultural Responsiveness and Community Partnership Development and partial implementation with Assessment and

Epidemiology capabilities. Furthermore, there is growing discourse in the field of public health and in Oregon of racism as a threat to public health. [4] [5] [6] [7] [8]

A fundamental lesson from this work is that communities want, deserve and need to be centered in all phases of survey modernization from instrument design, data collection, analysis, and deciding how the data is used. The call to action is larger than BRFSS and OHT/SHS surveys alone -- the call is to re-examine additional public health data collection systems and for communities to have a fundamentally different relationship with institutions; for institutions to relinquish power to the community; to share power and knowledge. BRFSS and OHT/SHS health data cannot be truly actionable to improve population health outcomes without the involvement of community leadership.

The lessons and recommendations from this survey modernization work with community partners should serve to inform Healthier Together Oregon State Health Improvement Plan (SHIP) specifically development of Social Determinants of Health metrics, OHA Strategic Data Plan, and OHA Accountability Metrics.

In order to uphold our OHA Acknowledgement to Community, public health survey data need to be actionable so we can be held accountable to the communities we serve.

OHA Acknowledgement to Community
- We acknowledge there are institutional, systemic and structural barriers that perpetuate inequality that have silenced the voices of communities over time.
- We are committed to partnerships, co-creation and co-ownership of solutions with communities disproportionately affected by health issues so that groups can actively participate in planning, implementing and evaluating efforts to address health issues.
- We recognize community-engaged health improvement is a long-term and adapting process.
- We are striving to engage with communities through deliberate, structured, emerging and best practice processes.
- We are striving to make engagement with public health effective for communities, especially those communities that experience institutional, systemic and structural barriers.

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[4] CDC Racism as Threat to Public Health https://www.cdc.gov/healthequity/racism-disparities/index.html
[5] AMA Racism as Threat to Public Health https://www.ama-assn.org/delivering-care/health-equity/ama-racism-threat-public-health
[6] APHA Racism and Health https://www.apha.org/topics-and-issues/health-equity/racism-and-health
[7] Alang S, Hardeman R, Karbeah J, Akosionu O, McGuire C, Abdi H, McApline D. White Supremacy and the Core Functions of Public Health. American Journal of Public Health 111, no 5 (May 1 2021): pp. 815-816
[8] Hardeman RR, Murphy KA, Karbeah J, Kozhimannil KB. Naming institutionalized racism in the public health literature: a systematic literature review. Public Health Rep. 2018; 133(3): 240-249.

APPENDIX 1
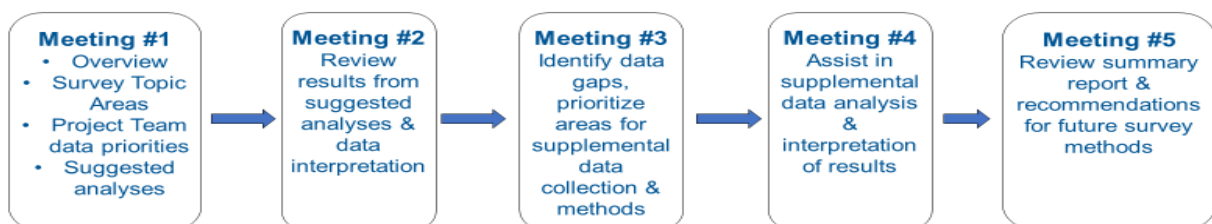
METHODS

Data Project Teams
Extensive partnership infrastructure building took place between October 2019- March 2020 to develop community specific data project teams of 4-5 individuals consisting of both researchers who are community members and have conducted community specific health related research and representatives from community-based organizations (CBOs).

Project team members reviewed the survey instruments, advised what analyses should be conducted of BRFSS and OHT data, interpreted results (e.g., what resonates and what doesn't, provide context, identify limitations, etc.), identified knowledge gaps in the data for the specific community, and suggested areas for community-led data collection that would provide additional context to the results. Under CCC guidance, team members also helped with designing supplemental data analysis and interpretation of supplemental data results. The project team guided the plans for summarizing results of all analysis in a brief data report and provided feedback on the report. The project team helped summarize lessons learned and recommendations for future survey methods.

As we went over the data areas of interest with the Latinx team, we understood data points that tracked with the experiences of Latinx folks on the ground. Sectors like food insecurity, access to health care, mental health, and sexual health provided notable data points. Members were interested to understand these data points by cross-checking them with variables like language, education level, region, and seeing if there were correlations between topics such as bullying and suicide data. They also wanted more details on how these data compared to other groups of color and more information on what data outside of these surveys could confirm these points. We also spent some time covering their confusion around understanding what some of the questions were measuring. They saw their communities in these data, but they also were concerned with the lack of context.

Team Meetings & Data Review

Project Team Process Goals

Meeting #1	**Meeting #2**	**Meeting #3**	**Meeting #4**	**Meeting #5**
• Overview • Survey Topic Areas • Project Team data priorities • Suggested analyses	Review results from suggested analyses & data interpretation	Identify data gaps, prioritize areas for supplemental data collection & methods	Assist in supplemental data analysis & interpretation of results	Review summary report & recommendations for future survey methods

Prior to meeting 1, project teams were sent the purpose of each survey, list of survey variables, respondent demographics, 2019 OHT instrument and report. They were asked what data they were more interested in exploring. During meeting 1, the purpose of the project was reviewed, project team values, data overview, list of variables available from the surveys, priorities for a brief data report. Focus was spent on what analysis of data they would like to see for meeting #2.

Prior to meeting 2, project team members were sent the data analysis they requested in meeting 1. They were asked prior to meeting 2 to share at the meeting if the results resonate with what they know of their community. Project team members were asked if and how the data resonate with what they know or are concerned about in their communities in Oregon. Team members identified limitations in the surveys from question design, interpretation, analysis and reporting.
During meeting 2 - Review requested results – what resonates, interpretation, data gaps, limitations of the data and team requested additional data for analysis.

Prior to meeting 3, project team members were sent the additional data analysis requested in meeting 2. They were also asked what ways they currently engage their communities during COVID and promising practices for engagement during this time. PDES shared literature review. During meeting 3, team members shared how they currently engage their communities during COVID and identified priority areas for supplemental data collection and methods for supplemental data collection to provide additional context to the survey results. They identified mental and behavioral health and health of youth as priority areas of focus.

Prior to meeting 4, project team members were sent results from CCC led additional data collection of youth. During meeting 4, team members reviewed results from CCC led additional data collection. Overview, methods and results from the BRFSS pilot were shared. The team began discussion of the integration of survey modernization components and what sustainable community engagement can look like.

Prior to meeting 5, project team members reviewed an outline of the executive summary report. During the meeting, main themes from their review of BRFSS and OHT were reviewed for feedback followed by areas where community led data collection addressed those themes. Project teams continued discussion of what continued community engagement can look like and how governmental public health can continue to build community capacity in BRFSS and going forward SHS.

Project team members were sent a draft of the report for feedback which was then included in the final report. The final report was shared with all project team members.

APPENDIX 2

<u>**COMMUNITY-LED DATA COLLECTION METHODS**</u>
The OHA Science and Epidemiology Council agreed to defer the project review to the workgroups themselves under the guidance of the Coalition of Communities of Color, specifically Drs. Andres Lopez and Mira Mohsini. We understand the protection of all participants will be of the utmost importance during this work and the review will assure its prioritization.

CCC facilitated data collection from December 2020 to March 2021 with the Latinx and Black/African American communities. The following two community engagement efforts were utilized.

<u>**Youth Health**</u>
Like ACEs, the team details how PYD questions are useless and damaging for the African American community and developed with a white middle-class population in mind, ignoring racism and focusing on individuals, not systems. These questions need to be developed with a trauma-informed lens, be conceptually related, dig deeper into causes, and co-constructed with youth.

It can be very traumatizing for youth to read a set a question that can lead them to feel like the blame is on them. How can you get information that is actionable and doesn't place the focus on the individual? Another concern was that the PYD questions need to be conceptually related. How meaningful and for whom is it to have questions about physical activity in the same index with questions about whether you have a trusted/supportive adult at school? Further, some related items do not tell us much. While increased exercise is associated with better health, many 11th graders who exercise reported poor health. What other types of questions do we need to ask to dig deeper? Lastly, relying on students can get us to those questions. The group recommended asking youth questions like how they felt about themselves and own their development? What questions would they ask of themselves? How would they frame it?

Youth health data collection included visiting two sections of an 11th grade virtual class on three separate occasions in November and December 2020, as well as an optional assignment. The class was led by Dr. Roberta Hunte, a member of the Black/African American project team. Drs. Andres Lopez and Mira Mohsini from the CCC were invited to engage and brainstorm with students about how data, and in particular data gathered through surveys, can relate to empathy. Students participated in several activities and discussions facilitated by Drs. Lopez and Mohsini to better understand how students perceive the connection between visibility, representation, and treatment of data that they provide through surveys. During class, students were also asked to provide feedback on the limitations of survey questions included in the OHT survey. An optional, not-for credit assignment also provided students with an opportunity to share specific feedback on their experiences of taking surveys and their thoughts on specific questions on the OHT survey. Students were not asked to share any personal information related to their health status. Students who opted-in for this assignment were viewed as subject

matter experts, who can provide insight into how survey questions often miss their most pressing concerns.

The assignment, which was an online survey, included the following sections:
- Overall feedback on student experiences of taking surveys, including questions about survey fatigue and how honestly students respond to questions.
- Reviewing and providing feedback on OHT survey questions on mental health, Positive Youth Development, and ACES. Students were asked what they think about these questions, what these questions miss, and what questions they would ask instead.
- Asking for any additional feedback, and thoughts on how government can build more empathy for their experiences.
- Demographic questions using REALD and SOGI questions.

This assignment did not ask specific health or risk behaviors. The assignment was optional and was not counted towards class credit. Students engaged with supplementary data collection methods for 2-3 hours and were compensated with a $50 gift card for their time and participation. Identifying information was only collected for the purpose of sending gift cards to survey respondents and was only accessed by Drs. Andres Lopez and Mira Mohsini (CCC staff members). All responses were securely stored on the CCC internal server and only Dr. Lopez and Dr. Mohsini had access to them (via password protected Qualtrics).

Demographics by Race, Ethnicity, Ancestry*

Black/African American (20) 27%	Latinx (26) 35%	Native American/ Indigenous (6) 8%	Asian (20) 27%	White (33) 45%
African American	Central American	American Indian	Chinese	Eastern European
Afro-Caribbean	Mexican	Indigenous Mexican, C. & S. American	Communities of Myanmar	Other White
Other African Black	Other Hispanic or Latino/a/x		Filipino/a	Western European
Somali			Japanese	

Black/African American (20) 27%	Latinx (26) 35%	Native American/ Indigenous (6) 8%	Asian (20) 27%	White (33) 45%
			Other Asian	
			Vietnamese	

n=74

*If more than one category was chosen, we designated it to the category identified by the respondent as their primary race, ethnicity, or ancestry.

Community-led Data Collection - Behavioral Health

A statewide survey on behavioral health was co-constructed with members of the Black/African American and Latinx survey modernization workgroups. The CCC, in collaboration with partners and community-based organizations, disseminated the survey within Black/African American and Latinx communities from January 2021 to April 2021. The online survey was available in English and Spanish and included 33 open- and closed-ended questions. While most respondents completed the survey independently, many chose to narrate their responses to someone who entered these into the online survey. Respondents were compensated with a $125 gift card upon completion of the survey. Identifying information was only collected for the purpose of sending gift cards to survey respondents and was only accessed by Drs. Andres Lopez and Mira Mohsini (CCC staff members). All responses were securely stored on the CCC internal server and only Dr. Lopez and Dr. Mohsini had access to them (via password protected Qualtrics). Due to the sensitive nature of the survey and to ensure harm mitigation while answering questions, a list of local mental and behavioral health resources was provided to respondents at the beginning and end of the survey.

Demographics by Race, Ethnicity, Ancestry*

Black/African American (n=123) 36%	Latinx (n=183) 54%
African	Afro-Latinx
African American	Central American

Black/African American (n=123) 36%	Latinx (n=183) 54%
Afro-Caribbean	El Salvadoran
Afro-Latinx	Guatemalan
Black	Indigenous Mexican
Ethiopian	Latina/o/x
Mexican	Mexican
Nigerian	
Somali	
South Sudanese	

n=340 (not included in this table are respondents who identified as Native American, Asian, Pacific Islander, and Middle Eastern)

*If more than one category was chosen, we designated it to the category identified by the respondent as their primary race, ethnicity, or ancestry.

Oregon Tribal Survey Modernization Project

Northwest Portland Area Indian Health Board
Northwest Tribal Epidemiology Center

NPAIHB

Final Report to Oregon Health Authority

July 2021

NORTHWEST PORTLAND AREA
INDIAN HEALTH BOARD

Table of Contents

Oregon Tribal Survey Modernization Project Personnel

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*Left tribal employment and workgroup in May 2021

Executive Summary

Background

The Northwest Portland Area Indian Health Board (NPAIHB) is a tribally-designated organization formed in 1972 that serves the 43 federally-recognized tribes in Idaho, Oregon, and Washington, each of which appoints a delegate to NPAIHB. The Northwest Tribal Epidemiology Center (NWTEC or the EpiCenter) was formed in 1996 as a department of the NPAIHB and is guided by the Public Health Committee of the NPAIHB, reporting to the tribal delegates.

Oregon is home to nine federally-recognized tribes:

- Burns Paiute Tribe
- Confederated Tribes of Coos, Lower Umpqua and Siuslaw Indians
- Confederated Tribes of Grand Ronde
- Confederated tribes of Siletz Indians
- Confederated Tribes of the Umatilla Indian Reservation
- Confederated Tribes of Warm Springs
- Coquille Indian Tribe
- Cow Creek Band of Umpqua Tribe of Indians
- Klamath Tribes

Each tribe has a unique history and culture, and is a sovereign government with its own elected leaders and policies for enrollment of its citizens. The state also has a sizeable and thriving population of AI/AN people living in urban areas and elsewhere throughout the state.

Tribal sovereignty is the inherent authority of a tribe to govern and protect the health, safety and welfare of tribal citizens. As sovereign nations, tribes are the owners of data for their citizens and should have primary control and voice in the use, interpretation, and disposition of data related to their citizens.

It is important to note that are many ways to define American Indian and Alaska Native (AI/AN) for data analysis purposes. As tribal citizenship is a political status, this makes the analysis and interpretation of data on AI/AN people more complex and different from analyses on other race and ethnicity groups. The NPAIHB and NWTEC use a broad definition of AI/AN, cross-referencing data with tribal registries to ensure all AI/AN are counted when providing data to tribes.

Project Overview

The purpose of the Oregon Tribal Survey Modernization workgroup was to review survey data from the Oregon Behavioral Risk Factor Surveillance System (BRFSS) and Oregon Health Teens (OHT) survey and highlight priority analyses, identify knowledge gaps, and generate topics and methods that can provide additional context to the results for AI/AN communities in Oregon and others who use the data. Given the condensed time frame of this work, our desire to not duplicate past or ongoing tribal data collection, and the need to respect tribal data ownership and sovereignty, the NPAIHB tribal workgroup elected not to engage in primary data collection and instead to review the methods and supplemental data of previously conducted Tribal BRFSS surveys.

The NPAIHB assembled a self-selected group of five participants for the project workgroup who responded to a general call for participation sent to tribal health leaders and staff at the nine Oregon tribes and NARA-NW, the Urban Indian Health Program in Portland. These five workgroup members were joined by four NPAIHB staff from the NWTEC. The NPAIHB hosted five two-hour Zoom meetings between May and July to discuss the OHT and BRFSS data as it relates to the AI/AN community and tribes.

The primary limitations of the workgroup process include the lack of representation from all nine Oregon tribes and urban Indian populations, as well as the condensed time frame and additional burdens facing public health professionals during the COVID-19 pandemic.

Tribal Workgroup Feedback

Defining AI/AN

The "best race" method of race classification does not accurately reflect the characteristics of the AI/AN population. Under this method, many respondents selecting multiple race/ethnicity who identify as AI/AN and/or are members of Oregon tribes are reclassified into other race or ethnicity categories, leading to underrepresentation of AI/AN respondents in survey data.

BRFSS Methods

The BRFSS survey is not conducted in a way that effectively reaches AI/AN communities. Outgoing calls from Oregon Health Authority are unlikely to be answered by potential AI/AN respondents.

Tribal Use of BRFSS Data

For members of the workgroup who are tribal health program staff, the BRFSS data are primarily useful only at the county level. They are therefore both too broad to be reflective of tribal members and exceedingly complicated to use for tribes whose service population is spread across multiple counties in Oregon.

It is important to note that while many tribes use BRFSS data to support funding applications, the analysis and reporting of tribe-specific BRFSS or OHT data by OHA or another non-tribal agency or organization to gain funding without tribal consultation would be an inherent tribal sovereignty conflict.

Additional funding is needed to meet pre-determined health needs, and additional surveys assessing need and amplifying disparities are not of great use to AI/AN communities.

Lack of Meaningful Context

Many OHT questions lack important cultural context or exclude non-Western practices. There is not sufficient follow-up on why students' needs are not being met, denying actionable information to alleviate barriers to healthcare access, for example.

Data Gaps

Some members of the workgroup were concerned about substantial missing data in the OHT and the lack of additional information on why questions were not answered.

The OHT and other future surveys would benefit from an increased focus on protective factors, particularly those that may come from involvement in cultural and tribal activities. Additional questions surrounding involvement in tribal and other cultural activities are needed.

Given the underlying difficulty of working with small sample sizes among AI/AN populations and tribes, greater efforts to incentivize school participation in OHT will yield more representative and useful data.

Tribal BRFSS Review

Upon request, the NPAIHB and the NWTEC support tribes in conducting tribe-specific BRFSS surveys that allow tribes to have full ownership of the data, ask questions relevant to their particular tribe and community, and reach tribal members more effectively and efficiently.

For tribal BRFSS projects, tribes have hired and trained tribal project site coordinators and tribal interviewers and provided a computer with needed survey and statistical software, or have contracted for these services with NWTEC and other public health professionals. BRFSS surveys have been adapted for use by multiple tribes to include information on point of care, use or need of specific services, follow-up questions on barriers to care, and participation in cultural activities.

Past tribal BRFSS participation was increased through community outreach, updating tribal phone registries, allowing for scheduled or in-person interviews, calling from a trusted phone number and compensating participation. Resulting data from Tribal BRFSS surveys have consistently provided highly relevant and actionable information to tribes about the needs of tribal members.

Data Use and Literature Review

Tribes are wary of data on AI/AN people being incorrectly understood or taken out of context, whether maliciously or unintentionally, when data are interpreted and reported by entities working outside of tribal contexts. This includes data reported by local and state public health agencies. datasets. To better understand where BRFSS and OHT AI/AN data are referenced, we reviewed data reports publicly available on OHA's website and conducted a literature review.

In the example of student absenteeism, OHA reports would benefit from concrete explanations of factors that may increase absenteeism among disadvantaged communities to better contextualize disparities.

Two studies identified in the literature review discussed the challenges of the "best race" methodology. The "best race" method has the potential to diminish the appearance of health disparities and ignore the burdens facing multi-race respondents in ways that have the potential to skew results.

The workgroup suggests enhanced tracking by OHA of BRFSS data requests and resulting data use to ensure that tribal data is protected.

Workgroup Recommendations to OHA

Actionable Data

- Work with tribes, the UIHP, and NWTEC to convene future discussions with health program staff, tribal leaders, and other stakeholders to better understand data priorities and the need for locally-actionable, tribal-specific data.

- Incorporate non-Western approaches to health and healthcare into survey questions.

Survey Methods

- Partner with tribes and tribal or urban AI/AN organizations to increase BRFSS participation and educate community members about the BRFSS and OHT.

- Include questions on protective factors, particularly involvement in tribal and AI/AN community activities.

Tribal and AI/AN Community Engagement

- Support Oregon tribes in conducting tribal BRFSS surveys.

- Protect tribal data and tribal sovereignty. Consider instituting additional data access requirements for non-AI/AN affiliated researchers and others to track how survey data are used, where data analyses or reports are posted or published, and ensure transparency and oversight by tribal and AI/AN communities.

Next Steps

- Seek additional feedback and input from tribes and AI/AN organizations, both from leadership and members of AI/AN communities, on how to improve BRFSS and OHT data quality and useability.

- Continued long-term engagement with AI/AN communities is critical to ensure that the initial recommendations in this report can be refined and expanded. OHA should utilize existing forums and recurring tribal meetings to further discuss survey modernization, but also consider holding listening sessions hosted by and within tribal and AI/AN communities.

NPAIHB and NWTEC

The Northwest Portland Area Indian Health Board (NPAIHB) is a tribal organization formed in 1972 that serves the 43 federally-recognized tribes in Idaho, Oregon, and Washington, each of which appoints a delegate to the NPAIHB. The Northwest Tribal Epidemiology Center (NWTEC) was formed in 1996 as a department of the NPAIHB and is guided by the Public Health Committee of the NPAIHB, reporting to the tribal delegates.

Figure 1: Map of Tribal Epidemiology Centers
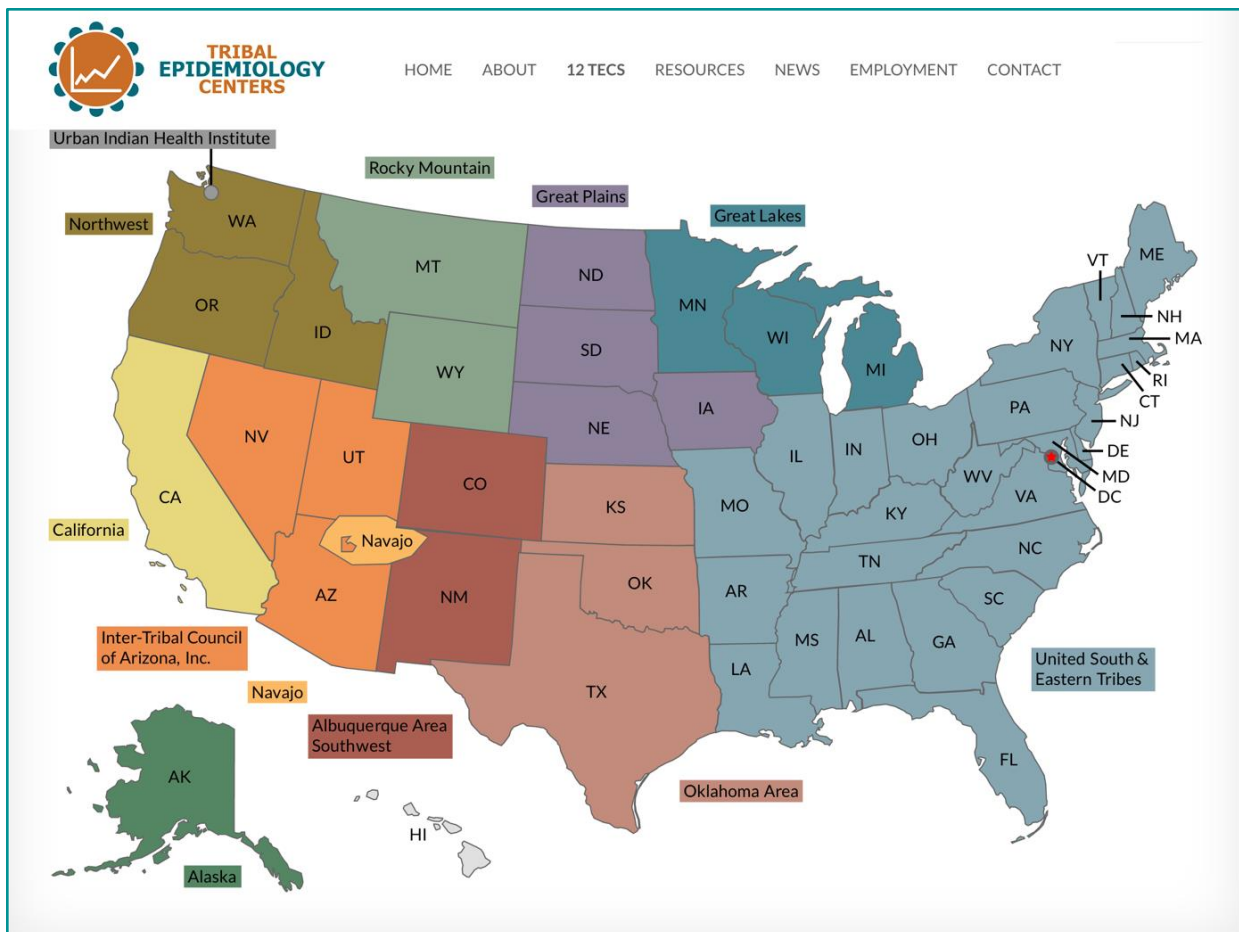
Source: www.tribalepicenters.org

Tribal Epidemiology Centers (TECs) were established as public health authorities for the purposes of the Health Insurance Portability and Accountability Act (HIPAA) through permanent reauthorization of the Indian Health Care Improvement Act (IHCIA) in 2010 (TribalEpiCenters.org). Each TEC functions independently but also as part of a national group called the TEC-Consortium. This status does not alter tribes' public health authority as sovereign nations, but is supportive of it. A US Health and Human Services (HHS) directive gives TECs access to HHS data systems and protected health information and the CDC provide technical assistance. Each Indian Health Service (IHS) Area must have TEC access. This allows TECs to act

as public health authorities at the request of tribes for data and provision of technical assistance.

Tribal Nations and the American Indian and Alaska Native People of Oregon

Oregon is home to nine federally-recognized tribes:

- Burns Paiute Tribe
- Confederated Tribes of Coos, Lower Umpqua and Siuslaw Indians
- Confederated Tribes of Grand Ronde
- Confederated Tribes of Siletz Indians
- Confederated Tribes of the Umatilla Indian Reservation
- Confederated Tribes of Warm Springs
- Coquille Indian Tribe
- Cow Creek Band of Umpqua Tribe of Indians
- Klamath Tribes

Figure 2: Map of Oregon's nine federally recognized tribes

Source: Oregon Health Authority

Oregon has the ninth-largest state-wide AI/AN population (self-reported AI/AN race alone or in combination with one or more other races) by percent of state residents at 2.99%, and the twelfth-largest by number of people at 128,380 (US Census Bureau, 2019a). In addition to tribal citizens residing on or near reservations and tribal lands, Oregon also has a sizeable and thriving population of American Indian and Alaska Native (AI/AN) people living in urban areas and

elsewhere in the state. The urban AI/AN population includes those who may be enrolled in federally-or state-recognized tribes outside of Oregon or descendants of AI/AN people indigenous to the continental US. According to the US Census Bureau American Community Survey (2019b-g), population estimates for AI/AN (alone or in combination) residents of the six metropolitan areas in Oregon are 53,067 in the Portland-Vancouver-Hillsboro, OR-WA Metro Area; 19,800 in the Salem, OR Metro Area; 12,642 in the Eugene-Springfield Metro Area, 6,423 in the Medford, OR Metro Area; 4,342 in the Albany-Lebanon, OR Metro Area; and 3,752 in the Bend, OR Metro Area; for a total estimated urban population of 100,026.

Federally-recognized tribes are recognized by the United States of America as sovereign nations. Under Article I, section 8 of the US Constitution, federally-recognized tribes are entitled to certain federal benefits, services, and protections. Federal Indian reservations are areas reserved by treaty or other agreements with the United States, and the US government holds title to the lands, in trust, for these permanent homelands for tribal nations.

In the 1950s, many Oregon tribes were terminated by the federal government. Termination revoked tribal sovereignty and land stewardship responsibility from tribes, often forcibly removing tribal members from their native land and shuttling them to poor urban areas. Six of the terminated Oregon tribes were later restored by the federal government. The terminated and restored tribes served by NPAIHB are the Confederated Tribes of Coos, Siuslaw & Lower Umpqua Indians; the Confederated Tribes of Grand Ronde; the Confederated Tribes of Siletz Indians; the Coquille Indian Tribe; the Cow Creek Band of Umpqua Tribe of Indians; and the Klamath Tribes. Confederated tribes comprise multiple bands, which were formed when the federal government moved decentralized villages (tribes) to a single shared location, often with disregard to ongoing and historical adversarial relationships.

The state of Oregon has had longstanding inter-governmental relationships with tribes and AI/AN communities, with a particularly strong emphasis on state-tribal relations over the last several decades. State agencies, including the Oregon Health Authority (OHA), engage regularly with the nine tribes and NARA-NW, the Portland-area Urban Indian Health Program (UIHP), including through tribal consultation and conferring with the UIHP (OHA Tribal Affairs).

Tribal Sovereignty

Tribal sovereignty is the inherent authority of a tribe to govern and protect the health, safety and welfare of tribal citizens. American Indians and Alaska Natives are citizens of sovereign tribal nations that have a unique legal and political relationship with the federal government that has been reaffirmed through numerous treaties, court cases, and Executive Orders. Tribal citizens are also citizens of the state in which they live and of the US, and all three governments – tribal, state, and federal – have a responsibility for the health and welfare of tribal members (Oregon Health Authority Tribal Affairs).

Tribal sovereignty means that each tribe is treated as a nation within a nation. These nations' members make their own laws within the tribe, act on their own behalf and sustain their living by adhering to tribal laws and regulations. Tribal sovereignty ensures the right for tribes to

choose their own future. Tribes are self-governing indigenous nations with legal, political, cultural, and spiritual authority. As sovereign nations, tribes are the owners of data for their citizens and should have primary control and voice in the use, interpretation, and disposition of data related to their citizens.

There is no single definition of American Indian/Alaska Native. While tribal citizenship is a political identity, state and federal systems do not systematically collect data on this status in a meaningful way. The race data that are collected by state and federal agencies are used to approximate tribal membership but do not address the nuances of AI/AN identity. For more discussion on this topic, see the Survey Classifications of AI/AN section on page 17 of this report.

> *"American Indian and Alaska Native tribal affiliation guidelines are varied and often based on complex tribal histories and sociopolitical processes which have led to multiple terms and levels of AI/AN identity. In addition, Tribes, Pueblos, and Nations can be federally recognized, state recognized, and unrecognized by either state or federal government, and people can self-identify as being AI/AN."*
>
> Haozous et al. (2014), Blood Politics

When producing data reports, the NPAIHB and the NWTEC opt to classify AI/AN race using any mention of American Indian, Alaska Native or tribal affiliation. Additionally, through the IDEA-NW Project (www.npaihb.org/idea-nw), the NWTEC cross-references state datasets with tribal registries in order to correct for race misclassification and provide accurate public health reports to Northwest tribes. AI/AN race is generally underreported on death certificate and state health databases, with estimates of misclassification ranging from 10-60% depending on the dataset (Jim et al., 2014). Misclassification is most often due to incorrect observations and assumptions by healthcare workers, instead of asking individuals to self-identify their race and ethnicity. Together, these methods allow the NWTEC to correct for racial misclassification and spotlight the people that we serve.

> *"American Indians and Alaska Natives are often incorrectly classified as another race (usually White) in vital statistics, cancer registries, and other public health datasets. In the Northwest, AI/AN misclassification in health datasets can range from 10-60%... Without accurate data, tribes are limited in their ability to identify and allocate resources to the areas of greatest need."*
>
> *IDEA-NW, NPAIHB/NWTEC*

Project Background

The Behavioral Risk Factor Surveillance System (BRFSS) and Oregon Healthy Teens (OHT) surveys are core components of Oregon Public Health Division's (OPHD) health assessment

system and are essential tools for program and policy planning, federal grant applications and legal advocacy. NPAIHB/NWTEC partnered with the Oregon Public Health Division and Program Design and Evaluation Services (PDES) to form a Survey Modernization Tribal Workgroup to gather feedback from tribal and AI/AN communities on the methods and data quality of the BRFSS and OHT surveys. The purpose of the workgroup was to review the survey data and highlight priority analyses, identify knowledge gaps and generate topics and methods that can provide additional context to the results for AI/AN communities in Oregon and other users of the data.

Given the condensed time frame of this work, our desire to not duplicate past or ongoing tribal data collection, and the need to respect tribal data ownership and sovereignty, the workgroup elected not to engage in primary data collection and instead to review the methods and supplemental data from previously conducted tribal BRFSS surveys. Six NPAIHB member tribes have completed a tribal BRFSS. The tribal BRFSS surveys were created as collaborative efforts between the NPAIHB and tribal administrations. While the state BRFSS uses phone calls as the primary data collection method, three of the tribes used phone calls, and two used the "door to door" method and conducted the survey in-person.

Limitations

Some of the limitations of this effort that we wish to highlight are:

- The views articulated by the workgroup reflect the perspectives of a small number of tribal health professionals and tribal members from a subset of Oregon tribes. Future workgroups and dialogue should incorporate urban Indian perspectives and feedback from all Oregon tribes.

- The scope of our project was somewhat limited by the relatively short duration of our contract with OHA, which started in November 2020. After a planning and outreach period between November 2020 and February 2021, the NPAIHB workgroup met five times between March and June 2021.

- Given this limited time frame and the unique considerations that must been taken when acquiring, requesting, and accessing tribal data, the workgroup decided early on to rely on secondary data for analysis and interpretation. The use of secondary data greatly reduced the comparability of the BRFSS/OHT data and the supplemental data review. While the workgroup discussed recently-used tribal BRFSS survey methods, the only publicly available tribal BRFSS data for presentation and discussion was from 2001. Accessing more current tribal BRFSS data would have required tribal approval, which was not feasible within our timeline.

- Other limitations included the departure of one workgroup member from her tribal public health position midway through the project timeline, as well as scheduling challenges, which impacted full workgroup attendance and continuity of discussion across meetings. The additional workload of the COVID-19 pandemic further stretched the availability of tribal health professionals and NPAIHB/NWTEC staff.

Workgroup Formation and Meeting Summaries

The NPAIHB put out a call for workgroup members to all nine Oregon tribal health programs and NARA-NW. This outreach included emails to Tribal Health Directors and tribal public health staff, targeted outreach to the staff of the 8 tribes and NARA-NW participating in NPAIHB's Oregon Tribal Public Health Improvement and assessment work under our primary contract with OHA, and announcements during NPAIHB meetings including our Quarterly Board Meeting in April 2021 and weekly tribal COVID-19 update sessions. Our goal was to recruit at least 5 workgroup members. As part of our process of identifying potential workgroup members, we asked them to complete a brief survey to identify key topic areas of interest.

Figure 3: Survey modernization project meeting workplan
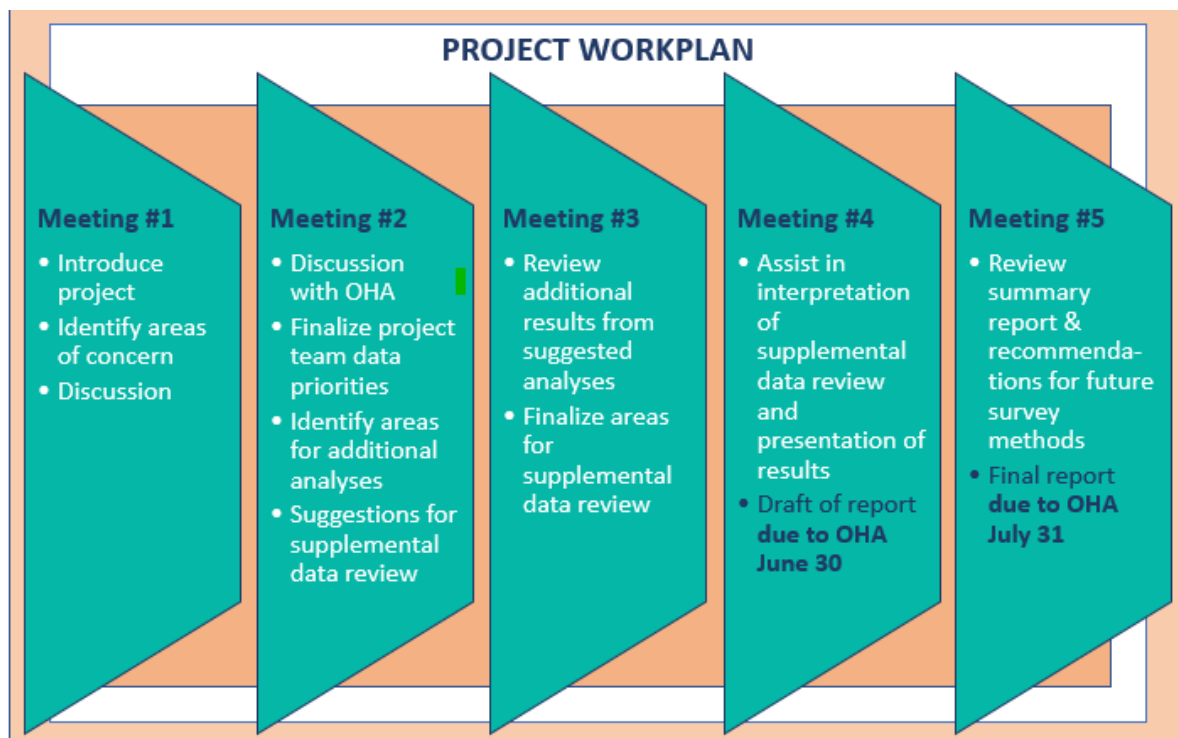
The tribal workgroup's process unfolded over six months, from February through July 2021:

- Pre-Meeting Survey: A majority of workgroup members identified key topic area priorities as adverse childhood events (ACEs), chronic health conditions, suicide and behavioral health. Additional topics of interest identified are listed below. Cross-tabulations on all topic areas for BRFSS and OHT were calculated and graphed for discussion.
    - **Adverse childhood events (ACEs)**
    - **Chronic health conditions**
    - **Suicide**
    - **Behavioral health**
    - Substance use disorder

- o Physical activity and nutrition
- o Healthcare access
- o School attendance

- Meeting #1 (March 1st): The workgroup reviewed the goals and objectives of NPAIHB's Oregon Survey Modernization project. There was initial concern from some workgroup members about the purpose of the project, particularly around supplementary AI/AN data collection, data ownership, and the potential lack of ability for all tribes to provide context for the data. There were concerns about the sharing of tribal data without proper tribal approvals, whether reports and data on AI/AN people and tribal members would be public-facing, and how the data would be protected. NPAIHB staff presented BRFSS and OHT data on some of the key health topics identified in the pre-meeting survey and held a facilitated discussion with workgroup members, with a focus on the importance of context in the survey questions.
  - o After the first meeting, the NPAIHB project team met individually with workgroup members to discuss concerns around the overall project goals and challenges of primary data collection, and to identify questions to be addressed by OHA staff at a future meeting.
- Meeting #2 (March 18th): The NPAIHB invited OHA to the second meeting to present on the purpose of the Oregon Survey Modernization project and provide an opportunity for discussion. The workgroup reviewed initial data analyses and discussed OHT and BRFSS methods.
  - o Workgroup members identified questions for suggested analyses between Meeting #2 and Meeting #3. Given the specialty and interests of the workgroup, the suggested analyses focused on the experiences, behaviors and environmental factors facing AI/AN teens in Oregon. Members of the workgroup listed the following questions (and associated OHT variables) for data review.
    - How is the general health of AI/AN teens in Oregon?
    - How is the mental health of AI/AN teens in Oregon?
    - How are AI/AN teens performing at school?
    - To what extent do the schools that AI/AN teens in Oregon attend feature harmful, dangerous or criminal behavior?
    - To what extent do AI/AN teens in Oregon suffer from money concerns?
    - How often do AI/AN teens in Oregon get enough sleep?
    - Do AI/AN teens in Oregon get sufficient exercise?
    - How often do AI/AN teens in Oregon eat healthy food?
    - To what extent do AI/AN teens in Oregon engage in risky or harmful behavior?
    - To what extent do AI/AN teens in Oregon use legal or illegal drugs?

- To what extent do AI/AN teens in Oregon experience abuse?

- To what extent are AI/AN teens engaged in their community?

- Meeting #3 (March 29th): The primary goal of this meeting was to review results from the suggested analyses submitted by workgroup members. The discussion focused on the importance of presenting missing values in survey results and the ambiguity and lack of meaningful context in many of the questions. The workgroup discussed supplemental data that was available for review.

- Meeting #4 (April 26th): Julia Dilley of PDES presented the results of the Oregon BRFSS Pilot Study. The workgroup reviewed comparable questions in the Oregon BRFSS and a sample tribal BRFSS, and discussed overarching themes of the data report.

- Meeting #5 (June 25th): Kerri Lopez of the NPAIHB presented on the tribal BRFSS project and results. The workgroup reviewed the results from the literature review and highlighted articles. We shared the current draft of this project report to OHA, and the workgroup was given two weeks to provide feedback.

- Post Meeting Period: workgroup members reviewed and provided feedback on this final report.

Data and resources utilized during meetings:

- BRFSS 4-year race reporting file

- OHT 2019 data file

- Overview of BRFSS and OHT topic areas with sample questions

- OHT suggested analyses requested from workgroup members after Meeting #2 (see Appendix B)

- Results of Oregon BRFSS Pilot Study

- Tribal BRFSS sample questions

- De-identified tribal BRFSS report

- Literature review of OHT/BRFSS data uses and data reports

Tribal Workgroup Feedback

Survey Classifications of AI/AN

The OHT and BRFSS surveys utilize multiple methods for race classification, including tribal affiliation, American Indian indicator and a "best race" classification. The "best race" classification is determined by the question, "Which one of these groups would you say best represents your race?" The classification used to define AI/AN respondents has a dramatic effect on the sample size. While 1,757 respondents identified themselves as American Indian in the 2015-2018 BRFSS, only 656 respondents are classified as AI/AN under the "best race" classification, with 976 respondents being classified as non-Hispanic White and 125 classified as other races or ethnicities. Similarly, among respondents who are enrolled members of an Oregon tribe, 18 were not categorized into AI/AN under the "best race" classification. This reclassification poses a tribal sovereignty conflict as members of Oregon tribes are by definition AI/AN and should be reported as such. The Bureau of Indian Affairs (BIA) notes that "there is no single federal or tribal criterion or standard that establishes a person's identity as American Indian or Alaska Native" but that a distinction must be drawn "when the term "American Indian" is used in an ethnological sense versus its use in a political/legal sense." In the BRFSS race-reporting file dataset provided, it is important to note that respondents who specified multiple races but did not choose one "best race" category were excluded from the dataset.

Figure 4: American Indian respondents by Best Race classification (BRFSS, 2015-2018)
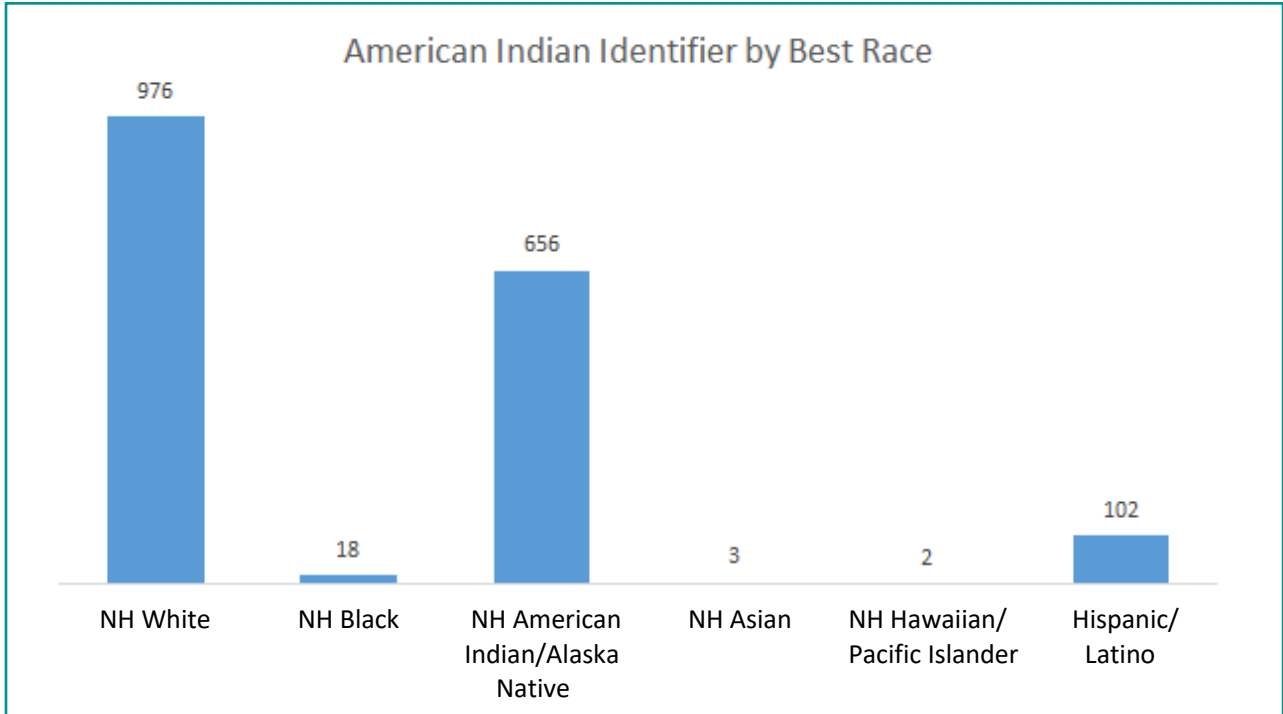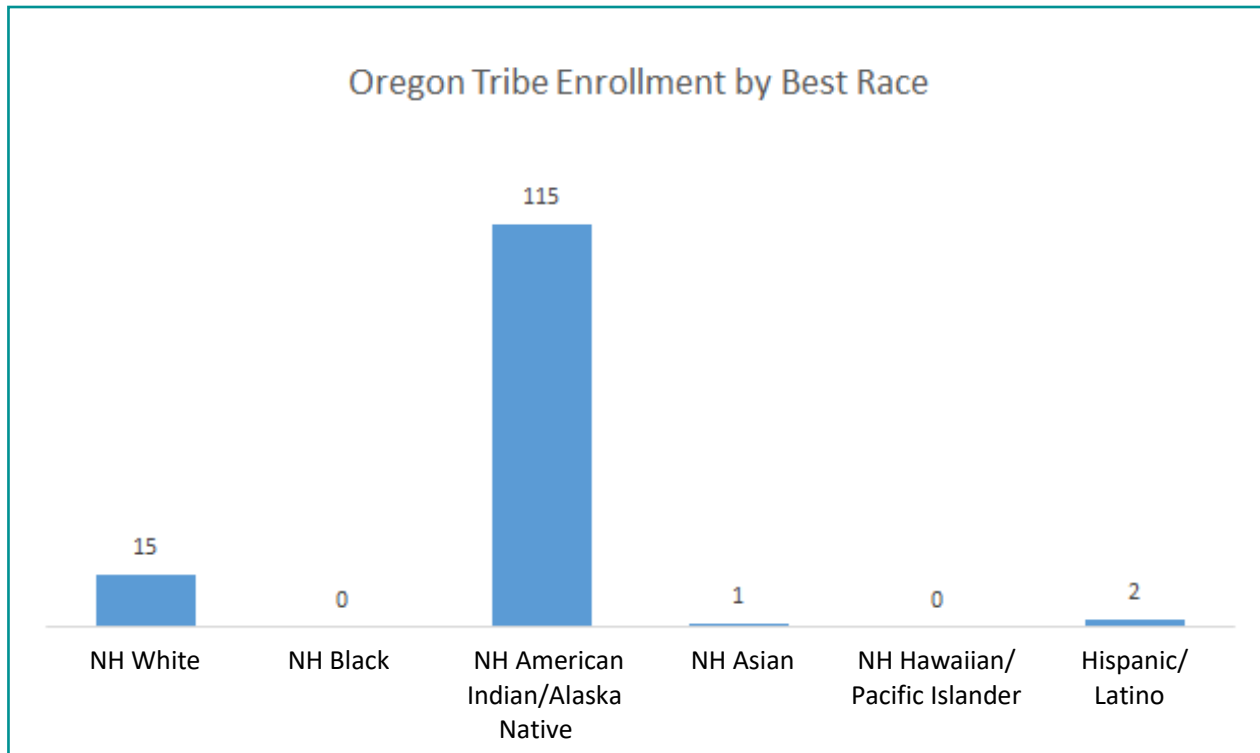

American Indian Identifier by Best Race

Category	Count
NH White	976
NH Black	18
NH American Indian/Alaska Native	656
NH Asian	3
NH Hawaiian/ Pacific Islander	2
Hispanic/ Latino	102

Stratifying the data into "best" or "preferred" race categories is a useful tool for making comparisons across distinct racial groups, but does not accurately reflect the characteristics of the AI/AN population or the political status of tribal members. The workgroup felt strongly that the primary role of improving BRFSS and OHT data for AI/AN communities should be to better inform and best serve Oregon tribes, not to generate more accurate stratifications and comparisons by race for researchers unaffiliated with tribes or AI/AN communities to analyze and distribute. Previous studies have found that allocating White multi-racial BRFSS respondents into the White category, as seen in the BRFSS "best race" method, has the potential to worsen the health profile of White respondents, giving the illusion of decreasing health disparities (Bratter et al., 2011). These definitions and classifications gain additional importance when considering the BRFSS survey methodology, which, among other factors, oversamples and weights respondents in accordance with their race and ethnicity, inherently valuing the responses of some AI/AN and tribal respondents more than those of others.

It is important to understand that tribes may have a variety of uses for BRFSS and OHT data and may have different criteria for identifying AI/AN residents and tribal members. Tribes may be interested in assessing the characteristics of:

- All registered tribal members (both in an outside Oregon)
- Those who utilize their tribal clinic or services
- The wider community residing within the tribal service area.

> *"In facilitating a tribe's rights to exercise sovereignty and facilitate good relations, researchers would benefit from having communities decide on inclusion criteria for AI/AN identity such as enrollment rolls, ancestry, or other specific variables as determined by the tribe."*
>
> Haozous et al. (2014), [Blood Politics](#)

The NPAIHB was asked to comment on Oregon's REALD methodology. REALD will allow respondents to identify their racial and ethnic identities in a wider variety of ways: first generally, and then in specific subcategories groupings that allow for write-in responses. The NPAIHB/NWTEC notes that in addition to American Indian and Alaska Native, the REALD AI/AN umbrella also includes Indigenous Mexican, Central and South American; Canadian Inuit, Metis and First Nation; and other AI/AN. While the latter are Indigenous and Native American, they do not fall under the political/legal category of American Indian/Alaska Native as tribal citizen or descendent, which may result in data inconsistencies.

Current BRFSS Methodology

The current BRFSS survey is not conducted in a way that reaches members of AI/AN communities as efficiently as possible. Many Oregon tribes and AI/AN people live in remote parts of the state, where cell phone coverage may be limited, making outreach via phone an unreliable recruitment method. The workgroup emphasized that there is deep distrust in government among AI/AN communities and that cold calls from the state could potentially be traumatic for AI/AN people. Many people are unfamiliar with OHA and the BRFSS, and the name "Oregon Health Authority" does not elicit trust or comfort. The cold-call method implies that the caller already knows who they are and where they are located, and so the respondent may be less inclined to answer honestly. For this reason, the phone survey methods might be less valid than online survey methods where there is greater anonymity. This feedback was affirmed by the results of the Oregon BRFSS Pilot study, which reached the majority of its AI/AN respondents through paper or online surveys and had minimal success with either inbound and outbound calls.

Tribal Use of BRFSS and OHT Data

Oregon tribes generally are interested in data from their associated Purchased/Referred Care Delivery Areas ([PRCDA](#)). PRCDAs are defined as counties that include a tribal reservation or have a common boundary with a tribal reservation, and are generally considered to delineate tribal service areas for healthcare delivery. One tribe may be associated with multiple PRCDA counties, and one PRDCA county may include members from multiple neighboring tribes. The following map shows Oregon PRCDA counties and associated tribes. For members of the workgroup working directly with tribes, the BRFSS data is primarily useful only at the county level and is therefore both too broad to be reflective of tribal members and exceedingly complicated for tribes whose members span across multiple counties. Using the data based on county designations requires complicated cross-tabulations and lacks important context, as not all AI/AN respondents within a county may belong to the nearest tribe and not all tribal

members live within neighboring counties. Workgroup members suggested that OHA conduct an assessment to ask the tribes directly whether they utilize BRFSS and OHT data, and how they wish to define their tribal service areas.

Figure 6: Map of Oregon tribes (blue) and PRCDA counties (orange)
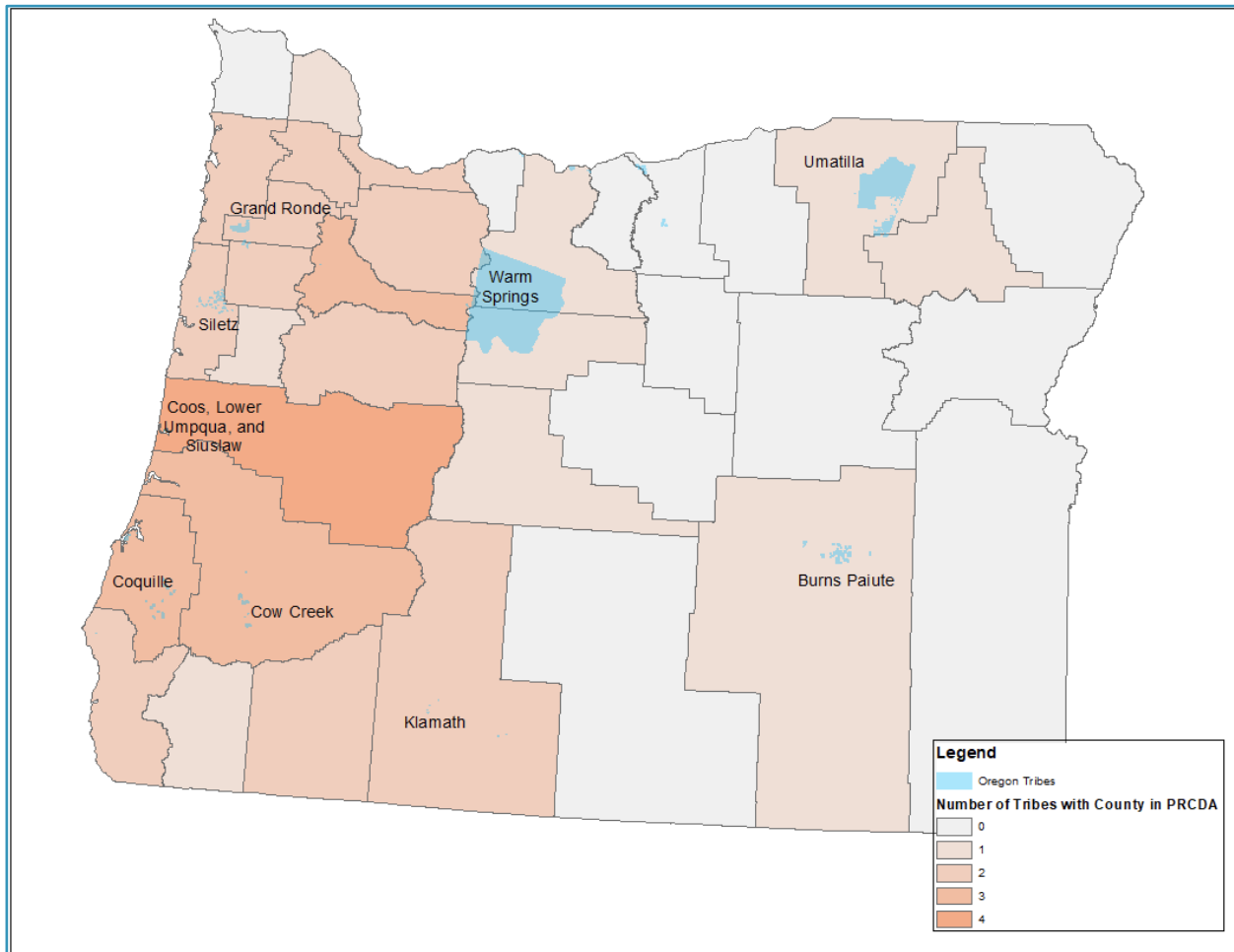
As part of our process, NPAIHB staff reached out to other projects within our organization that work with AI/AN teens to see how and when OHT data has been utilized. While OHT/YRBS has occasionally been used as an evaluation metric, these projects prefer to rely on internal surveys, focus groups, and adapted data sources such as the Oregon Native Youth Survey (ONYS) that can provide culturally-relevant data. ONYS is based upon the OHT, the Communities That Care (CTC) survey developed by Hawkins and Catalano at UW Seattle, and the Voices of Indian Teens survey (Dr. Spero Manson, PI). The Native American Rehabilitation Association of the Northwest (NARA-NW), which has been using the survey tool, added a peer suicide knowledge section from the Lifelines PreTest Questionnaire and additional questions about protective factors based on the concept of resiliency. ONYS was also reviewed for cultural appropriateness by a cultural advisory team at NARA-NW and is designed to be used along with focus groups for a better understanding of how the actual intervention activities are experienced by the youth.

While many tribes refer to BRFSS data in their funding applications, the use of AI/AN BRFSS or OHT data by non-AI/AN organizations in funding requests and project proposals, without consulting or conferring with tribes or UIHPs, can be considered problematic. Workgroup members felt strongly that tribes are very aware of the health inequities for AI/AN people and communities in Oregon, and that community-based participatory research and public health approaches that include AI/AN people at all stages should be promoted and supported. It is not enough that data be actionable, but also that the funding invested in addressing documented health inequities be flexible enough, and prioritize community-based recipients, to allow tribes and AI/AN-led organizations to guide the work.

> *"There is a need for more funding to meet the needs that have already been determined, and not simply more surveys to further assess needs and exemplify disparities."*
>
> *Tribal Workgroup Member*

Lack of Meaningful Context

Many OHT questions miss important cultural context. One example is the following OHT survey question: "During the past 30 days, did you ever sleep away from your parents or guardians because you were kicked out, ran away, or were abandoned?" A larger proportion of AI/AN teens responded "Yes" to this question than NHW teens, which taken out of context might be interpreted to mean that AI/AN teens face higher levels of conflict or neglect than NHW teens. However, for many AI/AN teens, who may live or often stay with other relatives often, sleeping away from home to stay with another family member during conflict may be a commonplace event, perhaps even a method of conflict management. The question as phrased could easily be interpreted as a standard coping strategy by AI/AN teens and point to higher conflict in AI/AN households by researchers who do not work in tribal communities.

The OHT question "I can work out my problems" was another example of a question that may be interpreted one way by AI/AN teens and another way by potential researchers. This question is part of the Positive Youth Development (PYD) section which aims to assess student's physical, emotional and social support. While the intent of the question is to assess student well-being and self-efficacy, the lack of contextual information for both the student and researchers makes it difficult to extrapolate meaningful information from the resulting responses.

The specificity of healthcare language in the OHT survey excludes non-Western modalities. For example, the question "During the past 12 months, did you have any physical health care needs that were not met? (Count any situation where you thought you should see a doctor, nurse, or other health professional.)" does not include an option to specify care from traditional healers. Including non-Western approaches in this question or asking a second question about access to traditional healers or other non-Western practitioners would more accurately capture the range of care students receive and may elucidate differences in students' access to Western and non-Western care.

Additionally, the OHT questions do not follow up with questions on why students are not able to access needed physical or mental healthcare. In order for the data to be actionable, more information on the reasons for unmet physical and mental health care needs are required, above and beyond the cost of care. Additional barriers to care may include: lack of insurance, inability to find a provider, owing money to the provider, transportation, difficulty finding/scheduling an appointment and lack of a care provider. See the tribal BRFSS section below for referenced sample questions.

Data Gaps

The tribal workgroup discussed the lack of information about missing data in the OHT. Many questions did not have an option for "I prefer not to answer." or "I do not understand the question." This information would be crucial to understanding how AI/AN students interpret the questions and where potential issues in question phrasing may result in non-response. This issue was exemplified in inconsistent responses around disability, in which a missing response may point to a "soft no." Pilot-testing some of these additional response options, or getting direct feedback from students who did not answer certain questions, could help uncover the reasons for missing data.

> *"Are there additional questions which could be added to the OHT survey to better show respect for tribal communities, or to better highlight the strengths of tribal communities?"*
>
> *Tribal Workgroup Member*

Workgroup members identified the positive youth development question "I volunteer to help others in my community" as an important indicator of perceived community engagement. Additional questions on community engagement would inform tribal and AI/AN organizations about student interest and participation in culturally-specific opportunities within their communities. OHT would benefit from an increased focus on protective factors particularly those that may come from involvement in cultural and tribal activities. Additional questions surrounding involvement in tribal and other cultural activities are needed.

The workgroup wanted to know how school participation in the OHT survey is encouraged, given that the response rate is only 30%. We understand that the OHT is not incentivized and that the low participation rate may be due to a lack of support for schools to conduct the surveys. Given the underlying difficulty of working with small sample sizes among AI/AN populations and tribes, greater efforts to increase school participation will yield more representative and useful data.

Tribal BRFSS Review

Upon request, NWTEC supports tribes in conducting tribe-specific tribal BRFSS surveys that allow tribes to have full ownership of the data, ask questions relevant to their particular tribe and community, and reach tribal members more effectively and efficiently. For example, the

Cowlitz Tribal BRFSS allowed the Cowlitz Tribe to investigate colorectal cancer screening rates among tribal members and evaluate the impact of the tribe's Colon Health Program. Each tribal BRFSS could be tailored to assess the unique health needs and services of each tribe:

- Tribes were funded to hire and train tribal project site coordinators and tribal interviewers and provided a computer with needed survey and statistical software, or have contracted for these services with NWTEC and other public health professionals. For the 2001 Tribal BRFSS project, over 80% of all individuals involved were American Indian or Alaska Native.

- Standard questions were adapted to encompass cultural activities, spiritual practices and health services relevant to the tribe.

- Questions were added to meet the health priorities and services of each tribe, such as:
  - Point of access for healthcare (tribal clinic vs. other)
  - Use of or need for specific services, such as Elders programs
  - Participation in cultural activities that support health and wellness, such as sweat lodges, canoe journeys, cultural relay races, etc.

These tribal BRFSS surveys have many benefits including greater underlying trust in tribal public health institutions. Tribal members are more willing to answer a phone call or reply to a survey from the tribe or a trusted partner. Tribes were able to adapt BRFSS methodology to achieve greater survey participation, such as:

- Provide information about the tribal BRFSS at community health centers

- Update tribal phone number registries in person before conducting the survey

- Provide the option for in-person or scheduled interviews

- Call from a trusted and local phone number

- Compensation for participation in the form of gift cards, cash incentives, or project promotional items

In the following examples, questions from a sample tribal BRFSS questionnaire are juxtaposed with a similar question or questions from the 2019 CDC BRFSS questionnaire (CDC, 2019). The tribal BRFSS questions contain wording and/or potential responses that provide additional context.

Figure 7: Barriers to Care: Sample Tribal BRFSS and CDC BRFSS Questions

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Tribal BRFSS   *CDC BRFSS:*

Now, I am going to ask you about medical care. When I say 'medical care,' I mean physical exams and lab tests.

6.6. Was there a time in the last 6 months when you needed medical care and didn't get it?

    1   YES
    2   NO☹GO TO Q6.8
    7   DON'T KNOW/NOT SURE☹GO TO Q6.8
    9   REFUSED☹GO TO Q6.8

6.7. What were the main reasons you went without needed medical care?

    01   IT COST TOO MUCH
    02   I DIDN'T HAVE INSURANCE
    03   THE DOCTOR WOULDN'T TAKE MY INSURANCE
    04   I OWED MONEY TO THE CARE PROVIDER
    05   I COULDN'T GET AN APPOINTMENT QUICKLY ENOUGH
    06   THE OFFICE WASN'T OPEN WHEN I COULD GET THERE
    10   I DIDN'T HAVE A DOCTOR
    77   DON'T KNOW/NOT SURE
    88   OTHER (SPECIFY) _____
    99   REFUSED

C03.03 Was there a time in the past 12 months when you needed to see a doctor but could not because of cost?

1 Yes
2 No
7 Don't know / Not sure
9 Refused

Figure 8: Treatment for High Blood Pressure: Sample Tribal BRFSS and CDC BRFSS Questions

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Tribal BRFSS   *CDC BRFSS:*

8.1. Have you had your blood pressure taken in the past 12 months?

    1   YES
    2   NO
    7   DON'T KNOW/NOT SURE
    9   REFUSED

8.2. Have you ever been told by a health provider that you had high blood pressure? [read only if necessary]: not including high blood pressure while pregnant.

    1   YES
    2   NO ☹GO TO NEXT SECTION
    7   DON'T KNOW/NOT SURE ☹GO TO NEXT SECTION
    9   REFUSED ☹GO TO NEXT SECTION

Now, I AM GOING TO READ A LIST OF REMEDIES YOU MAY BE USING TO TREAT YOUR HIGH BLOOD PRESSURE.

8.3. Are you using…

	READ CHOICES	YES	NO
A.	ORAL MEDICINE (MEDICINE YOU TAKE BY MOUTH)	1	2
B.	TRADITIONAL MEDICINE (PLEASE DESCRIBE) _____	1	2
C.	ACUPUNCTURE	1	2
D.	MASSAGE THERAPY	1	2
E.	DIET	1	2
F.	EXERCISE	1	2
G.	YOGA	1	2
H.	LIFESTYLE & WELLNESS COACH	1	2
I.	NO LONGER HAVE HIGH BLOOD PRESSURE	1	2
J.	OTHER (SPECIFY): _____	1	2

C04.01 Have you ever been told by a doctor, nurse, or other health professional that you have high blood pressure?

1 Yes
2 Yes, but female told only during pregnancy
3 No
4 Told borderline high or prehypertensive
7 Don't know / Not sure
9 Refused

C04.02 Are you currently taking prescription medicine for your high blood pressure?

    S 1 Yes
    2 No
    7 Don't know / Not sure
    9 Refused

Figure 9. Reasons for Not Exercising: Sample Tribal BRFSS Question

In the example to the right, the tribal BRFSS asks about reasons for not exercising. The 2019 CDC BRFSS has no analogous question.

7.4.   What is the **MOST** important reason why you did not exercise in the past month?

01	NOT ENOUGH TIME
02	NOT MOTIVATED, LAZY
03	PHYSICALLY UNABLE
04	DO NOT LIKE TO EXERCISE
05	DO NOT BELIEVE IN BENEFITS OF EXERCISE
06	GET ADEQUATE EXERCISE ON JOB OR FROM DAILY ACTIVITIES
08	LACK OF EXERCISE FACILITIES
10	WEATHER
11	OTHER (SPECIFY) _____
77	DON'T KNOW/ NOT SURE
99	REFUSED

A publicly-available report of six de-identified tribal BRFSS results (NPAIHB, 2003) elucidates issues that affect Northwest AI/AN communities as a whole while providing tribe-specific information that allows for more targeted health programs and policy-making. Conducting tribal BRFSS surveys allowed tribes to identify key issues specific to each individual tribe.

For example, Figure 10 shows the percent of respondents who received blood cholesterol testing differs widely from tribe to tribe and provides important context for whether a respondent has been told they have high blood pressure.

Figure 10. Tribal BRFSS Data Examples: Cholesterol

Figure 13. Percent of respondents who reported having their blood cholesterol checked in the past five years by BRFSS tribe, 2001 Northwest Tribal BRFSS Project

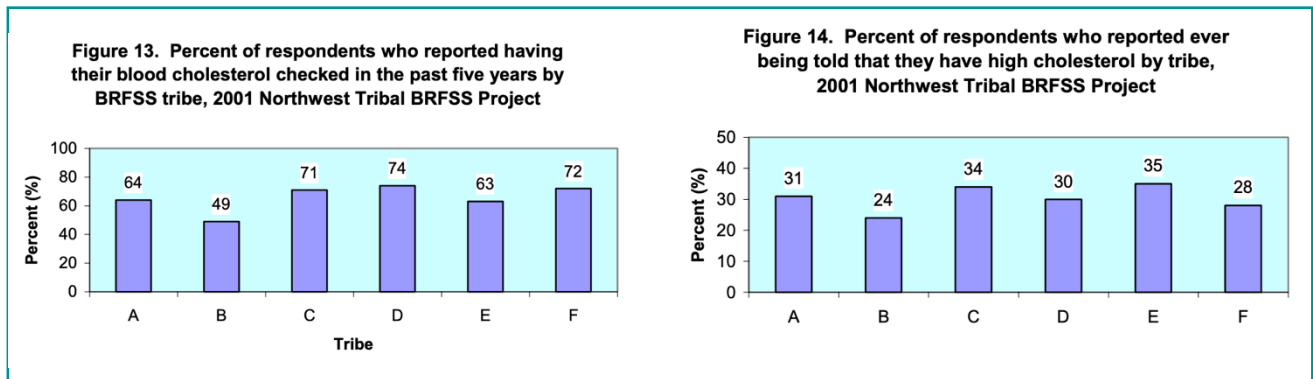Figure 14. Percent of respondents who reported ever being told that they have high cholesterol by tribe, 2001 Northwest Tribal BRFSS Project

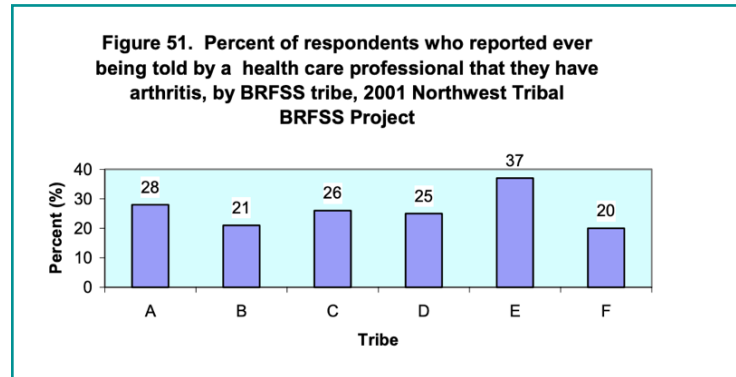Some tribes found higher than expected rates of arthritis and skin cancer and were able to develop relevant programs.

Figure 11. Tribal BRFSS Data Example: Arthritis

Figure 51. Percent of respondents who reported ever being told by a health care professional that they have arthritis, by BRFSS tribe, 2001 Northwest Tribal BRFSS Project

Figure 12. Tribal BRFSS Data Example: Current Smoking

Figure 33. Percent of men and women who reported current smoking by BRFSS tribe, 2001 Northwest Tribal BRFSS Project
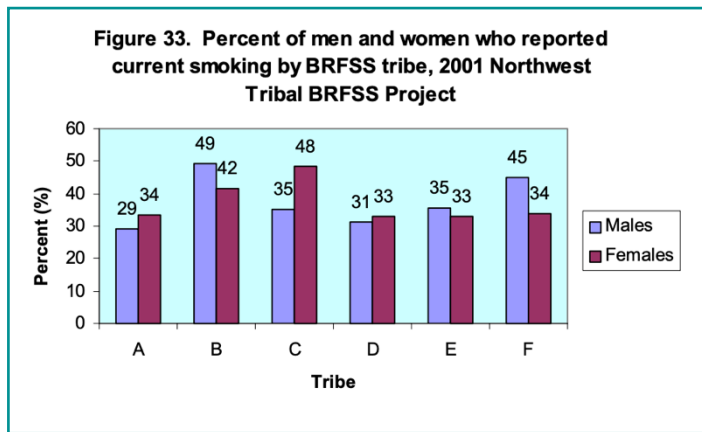
The patterns of tobacco use are also not uniform across tribes, necessitating different strategies to best meet the needs of the community.

The 2003 tribal BRFSS report highlighted the limitations of these efforts:

- Small numbers in small populations can result in inflated estimates.
- In order to attain meaningful sample sizes, tribal BRFSS results were not strictly randomly sampled. Data was not statistically weighted.
- Amount of funding available may affect sample size.

The tribal BRFSS projects provided tribes with relevant and actionable data about the needs of their population. With this information tribes were able to better understand the types of care accessed by tribal members and barriers to that care. The Tribal BRFSS Project unveiled previously unknown public health needs, such as high rates of skin cancer and arthritis, and allowed tribes to develop targeted programs to address these needs. Support from Oregon state in funding tribal BRFSS surveys would allow tribes to continue these meaningful data collection efforts and better serve tribal members.

Literature and Data Use Review

Tribes are wary of data on AI/AN people being incorrectly understood or taken out of context, whether maliciously or unintentionally, when data are interpreted and reported by entities working outside of tribal contexts. This includes data reported by local and state public health agencies.

> *"How [is OHA] going to control the interpretation of race stratifications, because it is a publicly accessible document? How will the data be protected so it isn't manipulated by outside parties?"*
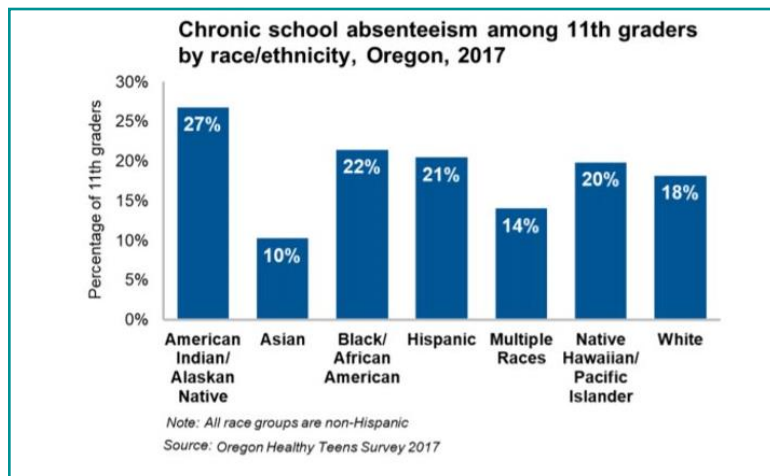>
> *Tribal Workgroup Member*

The workgroup was interested in how publicly-available BRFSS and OHT data have been used in the past, and how data has been interpreted. The NPAIHB project team reviewed data reports publicly available on OHA's website and conducted a literature review. Initially, we investigated publicly-available BRFSS and OHT data by performing an abbreviated independent search and review. We followed this with a request to CDC for a more thorough literature search. CDC conducted a literature search on five databases including Ovid (Medline and Embase), CINAHL, Scopus, and Sociological Abstracts. Search terms were modified for each database to capture articles that mentioned AI/AN BRFSS or OHT data in Idaho, Oregon, or Washington. CDC eliminated duplicate articles and sent NPAIHB a list of citations. As the project team reviewed the results, we excluded dissertations and articles that were captured using the search terms but did not directly address the requested subject matter.

OHA Data Use in Publications

In reviewing the OHA website for examples of how BRFSS and OHT data are reference in state publications and reports, two of the primary documents we explored were the State Health Assessment (SHA) and State Health Improvement Plan (SHIP). Oregon's SHA is updated every five years and provides important information for the development of the SHIP, which is Oregon's "five-year plan that identifies the state's health priorities with strategies to advance improvement and measures to monitor progress."

Lack of meaningful context when presenting comparisons across race groups perpetuates negative stereotypes and fails to address underlying causes of observed disparities. The OHA Social Determinants of Health Report (2019) on Chronic School Absenteeism discusses the relationship between high absenteeism and long-term academic challenges. Using 2017 OHA data, the report compares students with high and low absenteeism along A/B grades, depression in the past year, fair/poor physical and mental health and compares absenteeism across race. AI/AN 11th graders had the highest percent absenteeism at 27%.

Chronic school absenteeism among 11th graders by race/ethnicity, Oregon, 2017

Note: All race groups are non-Hispanic
Source: Oregon Healthy Teens Survey 2017

The OHA report states that "an array of social determinants can be barriers to students being in school, including poor health, poverty, transportation, and other familial and community factors," but does not provide context or examples for how these factors may disproportionately affect 11th grade student absenteeism among AI/AN students, such as the need for 11th graders to work to support themselves financially or the need to care for younger family members. Some of the tribal workgroup members have worked extensively with student populations and were able to provide more context around student absenteeism. In addition to social determinants, AI/AN students report missing school days due to cultural activities, ranging from dance performances to ceremonies that may last many days.

External Peer Reviewed Manuscripts

The results of the literature review yielded a variety of papers and topics, ranging from minority health surveillance reports to specific AI/AN determinants of health. We grouped the manuscripts into the following categories:

- General health surveillance (4)
- Cowlitz Tribal BRFSS results (1)
- Multiracial grouping (2)
- AI/AN-focused research (4)
- Research with no primary focus or results on AI/AN communities (4)

Two of the papers identified discussed the importance of multi-race ethnicity analyses in BRFSS. Bratter et al. (2018), found that the best race methodology has the potential to obscure health disparities when multiracial respondents identify with single-race groups. The authors found this to be particularly relevant for multiracial white AI/AN respondents who reported white as their best race while experiencing a greater number of health disadvantages than single-race white respondents. The importance of multi-race groups was exemplified by Asdigan et al. (2018) in comparison of AI/AN mental health burden estimates when using single and multi-race methods. In particular, the authors found that multi-race AI/AN respondents experienced a higher lifetime prevalence of diagnosed depressive disorder and frequent poor mental health and mental distress than both the single-race white group and single-race AI/AN group.

Together these studies highlight some of the substantial issues with best-race consolidation and the ways in which this method has the potential to drastically skew results.

Four of the manuscripts covered general health surveillance and four manuscripts were not primarily focused on AI/AN communities. Descriptions of these articles are available in Appendix A. A number of the manuscripts identified in the literature review discussed stigmatizing topics such as adverse childhood events and the effect of tribal casinos on tribal health. The NPAIHB project team was able to identify multiple co-authors who identify as AI/AN or who work closely with tribal organizations, but further research would be needed to establish what proportion of these articles were affiliated with tribal organizations. While we understand that OHA maintains data request and access records, maintaining resources for tracking who tribal data were released to and whether or not that group is affiliated with a tribe or tribal organization is essential to understanding how this data is distributed and how OHA is ensuring tribal data sovereignty is protected.

Recommendations

NPAIHB is grateful for the opportunity to convene a tribal workgroup to provide feedback to OHA on the current usefulness of the BRFSS and OHT survey data for AI/AN communities. However, we recognize that the project had numerous limitations (see pages 13-14), and we caution against considering this report to be comprehensive. The findings in this report should instead be taken as preliminary observations that require further exploration and investment.

As a summary of the discussion and suggestions by the tribal workgroup, we would like to offer the following recommendations to the Oregon Health Authority:

Actionable Data

- Localized tribal-specific data is preferable and more useful than state-wide or county-wide data.

- Incorporate non-Western approaches to health and healthcare (traditional healing, etc.) into BRFSS and OHT survey questions.

Survey Methods

- Partner with tribes and tribal or urban AI/AN organizations to increase BRFSS participation and educate community members about the BRFSS and OHT. Provide community members with information on who is collecting the data and for what purpose, and why their participation is important.

- Include questions on protective factors, particularly those that may come from involvement in tribal and AI/AN community activities.

Tribal and AI/AN Community Engagement

- Support Oregon tribes in conducting tribal BRFSS surveys. Further outreach and discussion are needed to determine specific tribal needs and make detailed recommendations.

- Protect tribal data and tribal sovereignty. Consider instituting requirements for researchers and others not affiliated with tribes or tribal/urban AI/AN organizations, who want to access and use AI/AN data held by the state. OHA should track how AI/AN data are used, where data analyses or reports are posted or published, and ensure tribal and AI/AN community oversight and transparency.

- Work with Oregon tribes, NARA-NW and other urban AI/AN organizations, and the NWTEC to convene future discussions with health program staff, tribal leaders, and other stakeholders to better understand data needs and priorities.

Next Steps

- Seek additional feedback and input from tribes and AI/AN organizations, both from leadership and community members, on how to improve BRFSS and OHT data quality and useability. While the 2021 workgroup process was an important step, much work remains to be done, and much more conversation is needed.

- Continued long-term engagement with AI/AN communities is critical to ensure that the initial recommendations in this report can be refined and expanded. OHA should utilize existing forums and recurring tribal meetings to further discuss survey modernization, but also consider holding listening sessions hosted by and within tribal and AI/AN communities.

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Appendix A
Literature Review Results

Tribal BRFSS

Maly, A.G., Steel, T.L., Fu, R., Lieberman, D.A., & Becker, T.M. (2014). "Colorectal cancer screening among American Indians in a Pacific Northwest tribe: Cowlitz tribal BRFSS project, 2009-2010." Public Health Reports 129(3): 280-288. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3982554/

Compares tribal BRFSS results to NHW BRFSS results to find that Cowlitz tribal members are receiving CRC screenings at the same rate as NHW, despite lower socioeconomic status. Attributes the lack of disparity to the tribe's Colon Health Program and encourages further investment.

Multiple Race Groupings

Asdigian, N.L., Running Bear, U., Beals, J., Manson, S.M., & Kaufman, C.E. (2018). "Mental health burden in a national sample of American Indian and Alaska Native adults: Differences between multiple-race and single-race subgroups." *Social Psychiatry and Psychiatric Epidemiology* 53(5):521-530. https://link.springer.com/article/10.1007%2Fs00127-018-1494-1

Authors find that multi-race AI/AN BRFSS respondents report worse mental health burden that single-race AI/AN or single-race NHW. Discusses limitations and issues surrounding single-race classification.

Bratter, J.L., & Gorman, B.K. (2011). "Does multiracial matter? A study of racial disparities in self-rated health." *Demography* 48(1): 127-152. https://link.springer.com/article/10.1007/s13524-010-0005-0

Authors find that placing multi-race respondents into single-race groupings can obscure health disparities between non-White and NHW respondents. This pattern was most apparent among AI/AN respondents who identified white as their best race while facing greater health disadvantages than single-race White respondents.

Elders

Goins, R.T., John, R., Hagan Hennessy, C., Denny, C.H., & Buchwald, D. (2006). "Determinants of Health-Related Quality of Life among Older American Indians and Alaska Natives." *Journal of Applied Gerontology* 25(1 supplement): 73S-88S. https://journals.sagepub.com/doi/abs/10.1177/0733464805283037

Found that AI/AN elders had a lower health-related quality of life (HRQoL) than the general population, with more than 1/3 of AI/AN elders report fair or poor self-rated

health. Age, education, income, employment, hypertension and obesity were also associated with HQRoL indicators.

Family Planning

Volscho, T.W. (2011). "Racism and Disparities in Women's Use of the Depo-Provera Injection in the Contemporary USA." *Critical Sociology* 37(5): 673-688. https://journals.sagepub.com/doi/10.1177/0896920510380948

Discusses current rates of Depo-Provera use among Black and AI/AN women in the context of racial sterilization abuse in the 1960-70s.

Mental Health

Giano, Z., Camplain, R. L., Camplain, C., Pro, G., Haberstroh, S., Baldwin, J. A., Wheeler, D.L., & Hubach, R. D. (2021). Adverse Childhood Events in American Indian/Alaska Native Populations. *American Journal of Preventive Medicine* 60(2), 213-221. https://www.sciencedirect.com/science/article/abs/pii/S0749379720304050

AI/AN respondents had higher ACEs scores than White, Black and Hispanic respondents. Women, those who are younger and have lower income, and sexual minorities reported higher ACEs score.

Tribal Casinos

Wolfe, B., Jakubowski, J., Haveman, R., & Courey, M. (2012). "The Income and Health Effects of Tribal Casino Gaming on American Indians." *Demography* 49(2): 499-524. https://link.springer.com/content/pdf/10.1007/s13524-012-0098-8.pdf

Uses BRFSS, tribal-level data, and county-level data to assess the effect of casino gaming on the income and health of tribal members. The authors generate estimates for positive health effects for tribal members.

General Health Surveillance

Liao, Y., Tucker, P., Okoro, C.A, Giles, W.H., Mokdad, A.H., & Bales Harris, V. (2004). "REACH 2010 Surveillance for Health Status in Minority Communities – United States, 2001-2002." Morbidity & Mortality Weekly Report. 53(6): 1-36. https://www.cdc.gov/mmwr/preview/mmwrhtml/ss5306a1.htm

Compares REACH and BRFSS results. Among AI/AN, report high levels of obesity, cigarette smoking, cardiovascular disease, hypertension, high blood cholesterol and diabetes.

Liao, Y., Bang, D., Cosgrove, S., Dulin, R., Harris, Z., Stewart, A., Taylor, A., White, S., Yatabe, G., Liburd, L., & Giles, W. (2011). "Surveillance of health status in minority communities – Racial and Ethnic Approaches to Community Health across the U.S. (REACH U.S.) Risk Factor Survey, United States, 2009." Morbidity & Mortality Weekly Report 60(SS06): 1-41. https://www.cdc.gov/mmwr/preview/mmwrhtml/ss6006a1.htm

Compares REACH and BRFSS results. Among AI/AN, report high levels of obesity, cigarette smoking, reported fair/poor health, hypertension, cardiovascular disease, diabetes and low mammography screening rates.

Towne, S.D. (2017). "Assessing Diabetes and Factors Associated with Foregoing Medical Care among Persons with Diabetes: Disparities Facing American Indian/Alaska Native, Black, Hispanic, Low Income, and Southern Adults in the U.S. (2011–2015)." https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5451915/

Authors assess rates of diabetes and foregoing medical care by race. AI/AN had one of the highest rates of diabetes through 2011-2015, in addition to high rates of forgone medical care.

Zahran, H. S., Kobau, R., Moriarty, D.G., Zack, M.M., Holt, J., & Donehoo, R. (2005). "Health-related quality of life surveillance--United States, 1993-2002." *Morbidity & Mortality Weekly Report.* 54(4): 1-35. https://www.cdc.gov/mmwr/preview/mmwrhtml/ss5404a1.htm

AI/AN reported higher rates of fair/poor health, physically and mentally unhealthy days, activity limitations. The authors attribute disparities to "factors such as income, education, occupation, disease status, behavioral risk factors, social and cultural factors (e.g., disenfranchisement and discrimination)."

Manuscripts not primarily focused on AI/AN respondents

Hahn, R., et al. (2000). "Health Risk Aversion, Health Risk Affinity, and Socio-Economic Position in the USA: The Demographics of Multiple Risk." *Health, Risk & Society* 2(3): 295-314. https://www.tandfonline.com/doi/abs/10.1080/713670164

Compares behavioral risk factors by race, including: smoking, heavy drinking, overweight, seatbelt use, vaccination and Pap smear, mammography and colorectal screening. Authors report that AI/AN and Black respondents had lower than expected prevalence of low risk factors and higher than expected prevalence of high-risk factors.

Kim, D., Subramanian, S.V., Gortmaker, S.L, & Kawachi, I. (2006). "US State-and County-Level Social Capital in Relation to Obesity and Physical Inactivity: A Multilevel, Multivariable Analysis." *Social Science & Medicine* 63(4): 1045-1059. https://www.sciencedirect.com/science/article/abs/pii/S0277953606001080

Examines the relationship between social capital and physical health, finding low efficacy of social capital on obesity among AI/AN. The authors attribute the lack of a relationship among AI/AN to high obesity rates and "the possible presence of much fewer social interactions with the general population (e.g., due to cultural/ethnic divides or, for some individuals, physical separation through residence on reservations) might also explain the relative inefficacy among them of social capital levels present in the general population."

Johnson, D.A., Jackson, C.L., Williams, N.J., & Alcantara, C. (2019). "Are sleep patterns influenced by race/ethnicity – a marker of relative advantage or disadvantage? Evidence to date." Nature and Science of Sleep 11: 79-95. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6664254/pdf/nss-11-79.pdf

Discusses sleep duration by race and ethnicity. Authors find that AI/AN respondents had a lower age-adjusted prevalence of healthy sleep and higher levels of insufficient sleep.

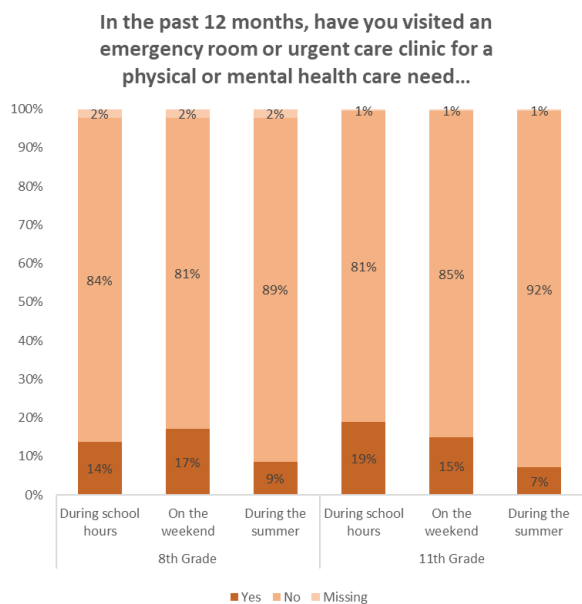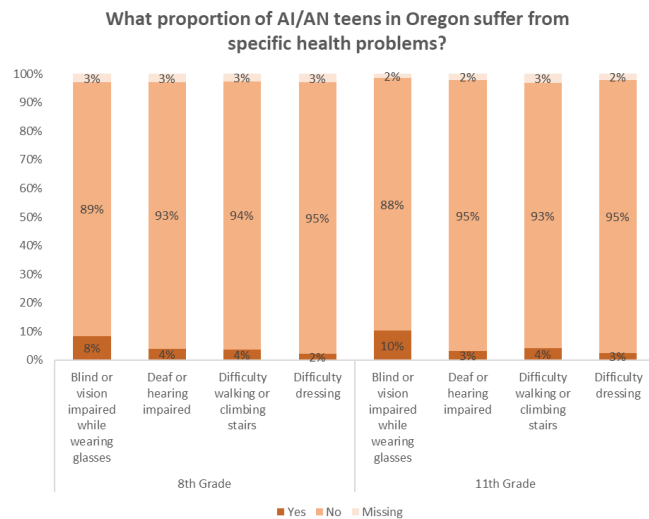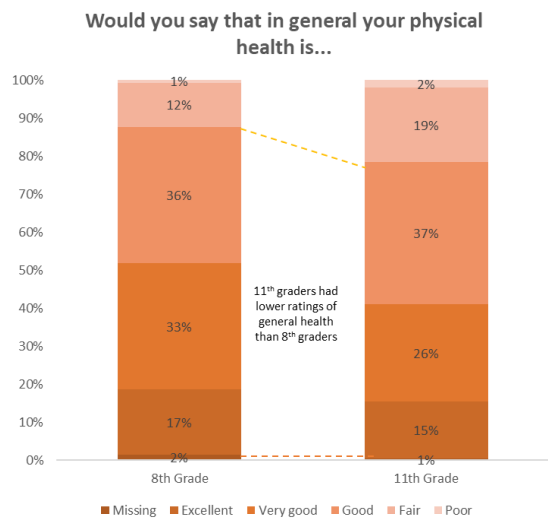Tuthill, Z., Denney, J.T., & Gorman, B. (2020). "Racial disparities in health and health behaviors among gay, lesbian, bisexual and heterosexual men and women in the BRFSS-SOP." *Ethnicity and Health* 25(2): 177-188. https://www.tandfonline.com/doi/full/10.1080/13557858.2017.1414157

The report examines health and health behaviors among sexual minorities. Among AI/AN, bisexuals had lower odds of obesity than heterosexuals.

How is the general health of AI/AN teens in Oregon?

Would you say that in general your physical health is…

11th graders had lower ratings of general health than 8th graders

Legend: Missing, Excellent, Very good, Good, Fair, Poor

8th Grade: 1%, 12%, 36%, 33%, 17%, 2%
11th Grade: 2%, 19%, 37%, 26%, 15%, 1%

What proportion of AI/AN teens in Oregon suffer from specific health problems?

8th Grade — Blind or vision impaired while wearing glasses: 3% / 89% / 8%; Deaf or hearing impaired: 3% / 93% / 4%; Difficulty walking or climbing stairs: 3% / 94% / 4%; Difficulty dressing: 3% / 95% / 2%

11th Grade — Blind or vision impaired while wearing glasses: 2% / 88% / 10%; Deaf or hearing impaired: 2% / 95% / 3%; Difficulty walking or climbing stairs: 3% / 93% / 4%; Difficulty dressing: 2% / 95% / 3%

Legend: Yes, No, Missing

In the past 12 months, have you visited an emergency room or urgent care clinic for a physical or mental health care need…

8th Grade — During school hours: 2% / 84% / 14%; On the weekend: 2% / 81% / 17%; During the summer: 2% / 89% / 9%

11th Grade — During school hours: 1% / 81% / 19%; On the weekend: 1% / 85% / 15%; During the summer: 1% / 92% / 7%

Legend: Yes, No, Missing

Do AI/AN teens in Oregon have suitable access to general healthcare?

8th Grade — School has School-Based Healthcare: 3% / 46% / 15% / 36%; Unmet physical health needs: 3% / 78% / 19%

11th Grade — School has School-Based Healthcare: 4% / 29% / 14% / 53%; Unmet physical health needs: 1% / 84% / 16%

Legend: Yes, No, Don't Know, Missing

How is the mental health of the AI/AN teens in Oregon?

Would you say that in general your emotional and mental health is...

8th Grade: Poor 13%, Fair 23%, Good 29%, Very good 19%, Excellent 15%, Missing 2%

11th Grade: Poor 14%, Fair 28%, Good 28%, Very good 16%, Excellent 13%, Missing 1%
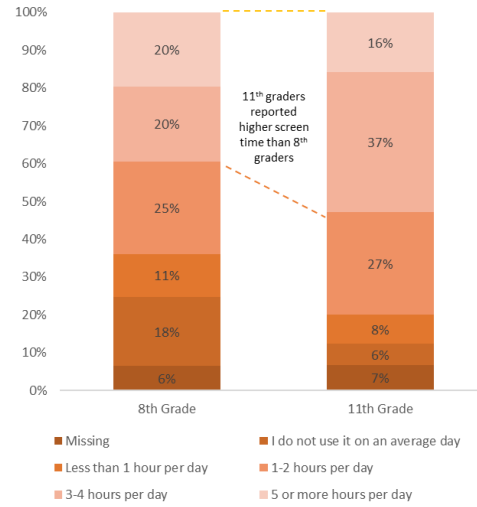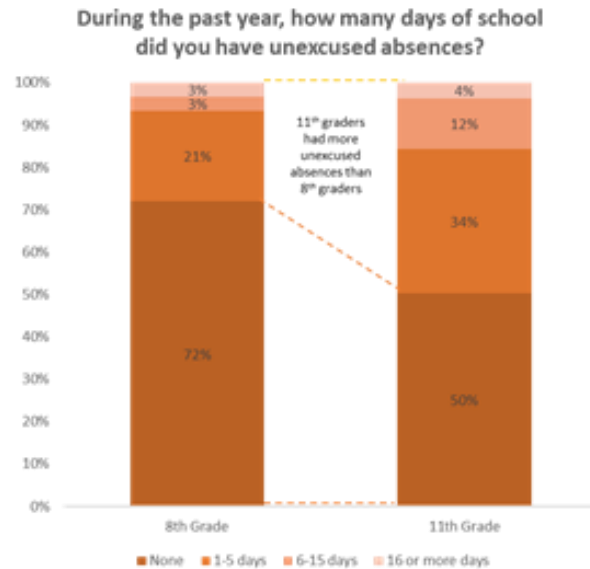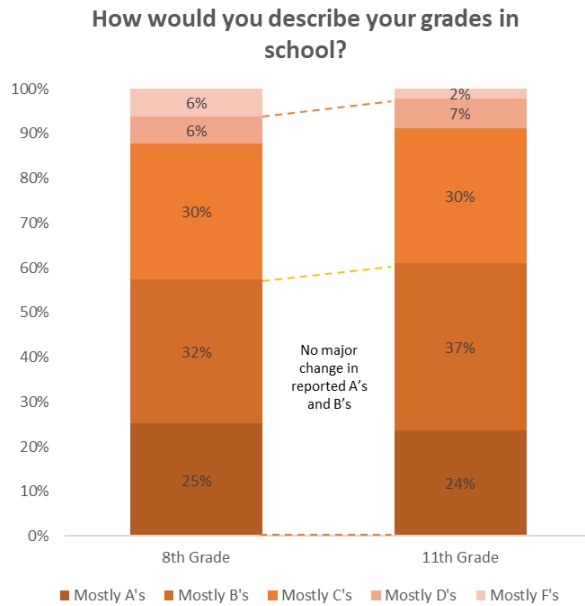
11th graders reported poorer mental health than 8th graders

Missing Excellent Very good Good Fair Poor

On an average day, how many hours do you use social media?

8th Grade: 5 or more hours per day 20%, 3-4 hours per day 20%, 1-2 hours per day 25%, Less than 1 hour per day 11%, I do not use it on an average day 18%, Missing 6%

11th Grade: 5 or more hours per day 16%, 3-4 hours per day 37%, 1-2 hours per day 27%, Less than 1 hour per day 8%, I do not use it on an average day 6%, Missing 7%

11th graders reported higher screen time than 8th graders

Missing I do not use it on an average day Less than 1 hour per day 1-2 hours per day 3-4 hours per day 5 or more hours per day

I can work out my problems.

8th Grade: Not true at all 5%, A little true 24%, Pretty much true 39%, Very much true 30%, Missing 3%

11th Grade: Not true at all 2%, A little true 16%, Pretty much true 38%, Very much true 44%, Missing 1%

11th graders reported higher self efficacy than 8th graders

Missing Very much true Pretty much true A little true Not true at all

How are AI/AN teens performing at school?

How would you describe your grades in school?

	8th Grade	11th Grade
Mostly F's	6%	2%
Mostly D's	6%	7%
Mostly C's	30%	30%
Mostly B's	32%	37%
Mostly A's	25%	24%

No major change in reported A's and B's

Legend: Mostly A's, Mostly B's, Mostly C's, Mostly D's, Mostly F's

During the past year, how many days of school did you have unexcused absences?

	8th Grade	11th Grade
16 or more days	3%	4%
6-15 days	3%	12%
1-5 days	21%	34%
None	72%	50%

11th graders had more unexcused absences than 8th graders

Legend: None, 1-5 days, 6-15 days, 16 or more days
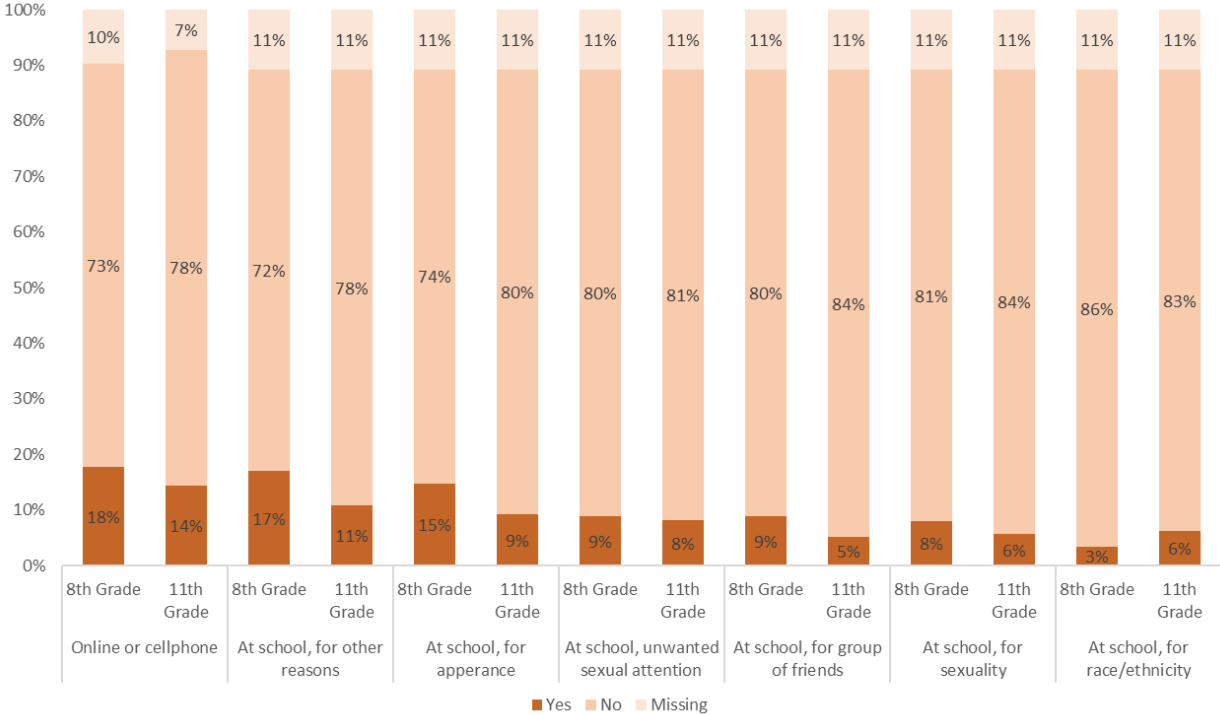
To what extent do the schools that AI/AN teens attend in Oregon feature harmful, dangerous, or criminal behavior?

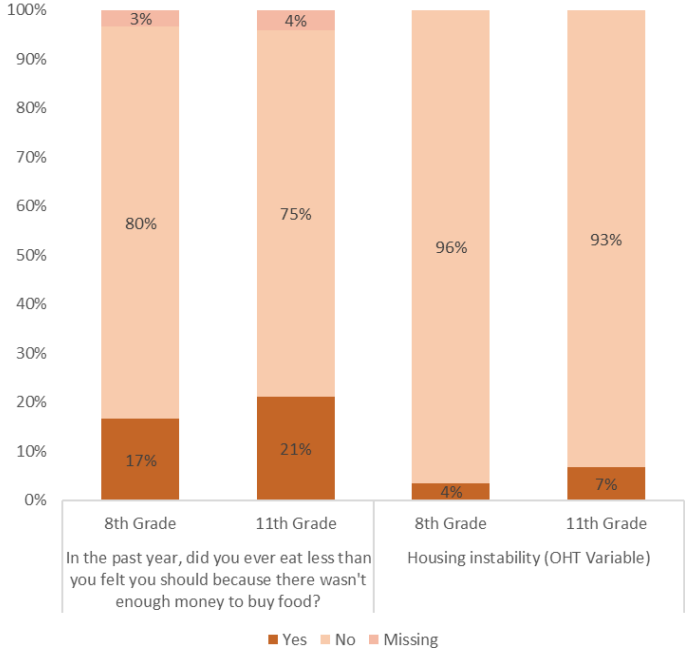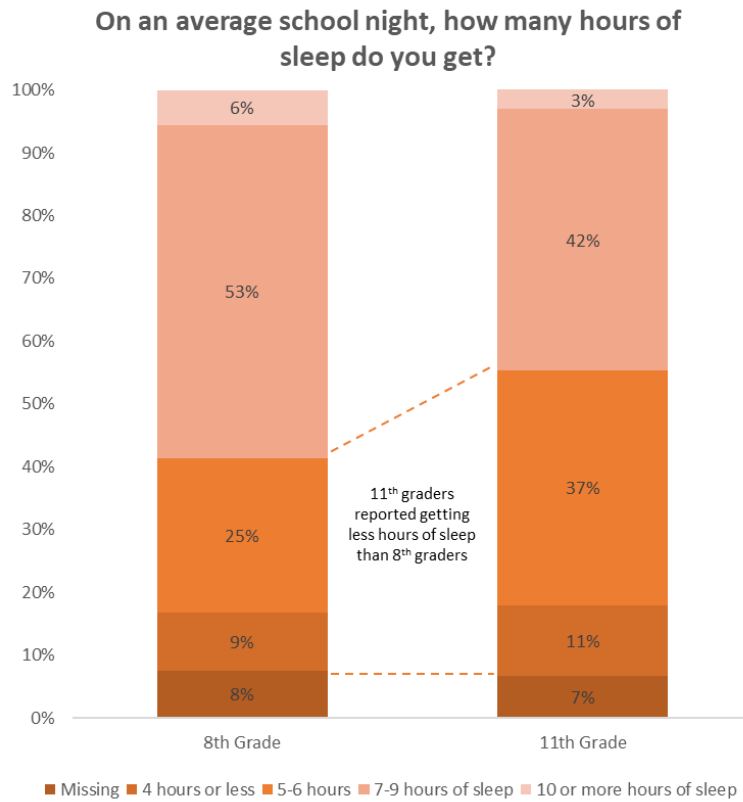## During the past 12 months, how many times were you in a physical fight on school property?

	8th Grade	11th Grade
10 or more times	1%	1%
4-9 times	4%	1%
2-3 times	7%	3%
1 time	9%	5%
Never	70%	82%
Missing	9%	9%

Decreased fighting at school among 11th graders

Legend: Missing, Never, 1 time, 2-3 times, 4-9 times, 10 or more times

Experiences of Bullying

	Online or cellphone		At school, for other reasons		At school, for apperance		At school, unwanted sexual attention		At school, for group of friends		At school, for sexuality		At school, for race/ethnicity	
	8th Grade	11th Grade	8th Grade	11th Grade	8th Grade	11th Grade	8th Grade	11th Grade	8th Grade	11th Grade	8th Grade	11th Grade	8th Grade	11th Grade
Missing	10%	7%	11%	11%	11%	11%	11%	11%	11%	11%	11%	11%	11%	11%
No	73%	78%	72%	78%	74%	80%	80%	81%	80%	84%	81%	84%	86%	83%
Yes	18%	14%	17%	11%	15%	9%	9%	8%	9%	5%	8%	6%	3%	6%

Yes ■ No ■ Missing

To what extent do AI/AN teens in Oregon suffer from money concerns?

Economic Wellbeing

	In the past year, did you ever eat less than you felt you should because there wasn't enough money to buy food?		Housing instability (OHT Variable)	
	8th Grade	11th Grade	8th Grade	11th Grade
Missing	3%	4%		
No	80%	75%	96%	93%
Yes	17%	21%	4%	7%

Yes ■ No ■ Missing

How often do AI/AN teens in Oregon get enough sleep?

On an average school night, how many hours of sleep do you get?

11th graders reported getting less hours of sleep than 8th graders

Legend: Missing | 4 hours or less | 5-6 hours | 7-9 hours of sleep | 10 or more hours of sleep

8th Grade: 8%, 9%, 25%, 53%, 6%
11th Grade: 7%, 11%, 37%, 42%, 3%

Do AI/AN teens in Oregon get sufficient exercise?

In the past week, on how many days were you physically active for a total of at least 60 minutes per day?

Greater reports of daily/almost daily exercise among 11th graders

11th graders report little to no exercise more than 8th graders

Legend: Missing | Never | 1-2 days | 3-5 days | 6-7 days

8th Grade: 7%, 8%, 14%, 35%, 36%
11th Grade: 8%, 11%, 12%, 30%, 39%

On how many of the past week did you do exercises to strengthen or tone your muscles, such as push-ups, sit-ups, or weight lifting?

More 11th graders reported no strength building exercise

Legend: Missing | Never | 1-2 days | 3-5 days | 6-7 days

8th Grade: 7%, 19%, 22%, 33%, 19%
11th Grade: 8%, 25%, 18%, 30%, 19%

How often do AI/AN teens in Oregon eat healthy foods?

During the past week, did you eat/drink...

Plain water	98%
Fruit	91%
Other vegetables	83%
Plain milk	76%
100% Fruit Juices	68%
Green salad	62%
Potatoes	61%
Carrots	53%
Energy drinks	42%
Sports drinks	55%
Flavored milk	52%

8th and 11th graders reported consuming healthy foods and beverages more often than unhealthy foods and vegetables

■ 8th Grade ■ 11th Grade

To what extent do AI/AN teens in Oregon engage in risky or harmful behavior?

In the past 30 days, have you bet on...

	8th Grade	11th Grade
Playing games of personal skill	Yes 13% / No 69% / Missing 17%	Yes 12% / No 77% / Missing 10%
Playing poker	Yes 9% / No 74% / Missing 17%	Yes 7% / No 83% / Missing 10%
Actual sporting events	Yes 9% / No 77% / Missing 15%	Yes 7% / No 84% / Missing 9%
Playing dice or coin flips	Yes 6% / No 77% / Missing 17%	Yes 6% / No 84% / Missing 10%
Fantasy Sports	Yes 2% / No 81% / Missing 17%	Yes 3% / No 87% / Missing 10%

■ Yes ■ No ■ Missing

To what extent do AI/AN teens in Oregon use legal and illegal drugs?

During the past 30 days, on how many days did you..

Legend: Missing | Never | 1-2 days | 3-9 days | 10 + days

To what extent do AI/AN teens in Oregon experience abuse?

Experiences of Abuse Among 11th Graders

Legend: Yes | No | Missing

THIS IS THE WAY WE RISE

Pacific Islander Data Modernization in Oregon **2021**

Table of Contents

THIS IS THE WAY WE RISE
Pacific Islander Data Modernization in Oregon

Acknowledgements

DEDICATION

This report is dedicated to our home, Oceania, and the ancestors who never let us forget the waters that birthed us.

LAND ACKNOWLEDGEMENT

The Lenape story about the Great Turtle is shared by the Indigenous peoples of the Northeastern Woodlands and carries throughout all of North America. Through these stories, we continue to learn about those who have stewarded these lands since time immemorial. We would like to express our appreciation and respect of the Indigenous peoples' inherent kinship beliefs when it comes to the land, especially since those beliefs were restricted for so long. The United States was built on broken treaties. The lasting effects of federal and state policies, both past and present, have systematically oppressed Alaska Natives and American Indians for hundreds of years. It is on all of us, whether we are descendants of colonizers or inhabitants of stolen land, to decolonize and act in solidarity with Indigenous peoples.

We would like to honor and acknowledge the Indigenous peoples and rightful owners of this occupied land in which we do our work: the Klamath tribe of the Southern Oregon plateau; the Burns Paiute of the high-desert east; the Coquille of Southern Oregon's coastal forests; the Confederated Tribes of Grand Ronde in the northern Coast Range; the Cow Creek Band of Umpqua in the Southern Oregon foothills; the Confederated Tribes of Umatilla in the Blue Mountains; the Confederated Tribes of Siletz in Oregon's northern rainforests; the Confederated Tribes of Coos, Lower Umpqua, and Siuslaw on the windblown southern coast; the Confederated Tribes of Warm Springs on the sunny eastern slopes of the Oregon Cascades; and all indigenous communities who hold ancestral ties to this land.[1]

[1] Adapted from the Land Acknowledgement written by Ka Lei Hali'a O Ka Lokelani utilizing www.native-land.ca

Contributors

Pacific Islander Data Modernization is a collaboration between leaders of Oregon's diverse Pacific Islander communities, local Pacific Islander-led community-based organizations, Pacific Islander community researchers, and state and county government staff. This work was funded by the Oregon Health Authority's Public Health Division and supported by the Multnomah County Health Department.

This body of work represents the collective effort to tell the stories of the people of Oceania living in Oregon. This work would not be possible without the wisdom, partnership, and dedication of Oregon's Pacific Islander communities. The contributors are listed below in alphabetical order by name/last name:

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    of Oregon and SW Washington (KALO HCC)
Le'o 'o e 'OFA
Living Islands
Micronesian Islander Community (MIC)
Oregon Pacific Islander Coalition (OPIC)
Tongan Women's Association
United Territories of Pacific Islanders Alliance -
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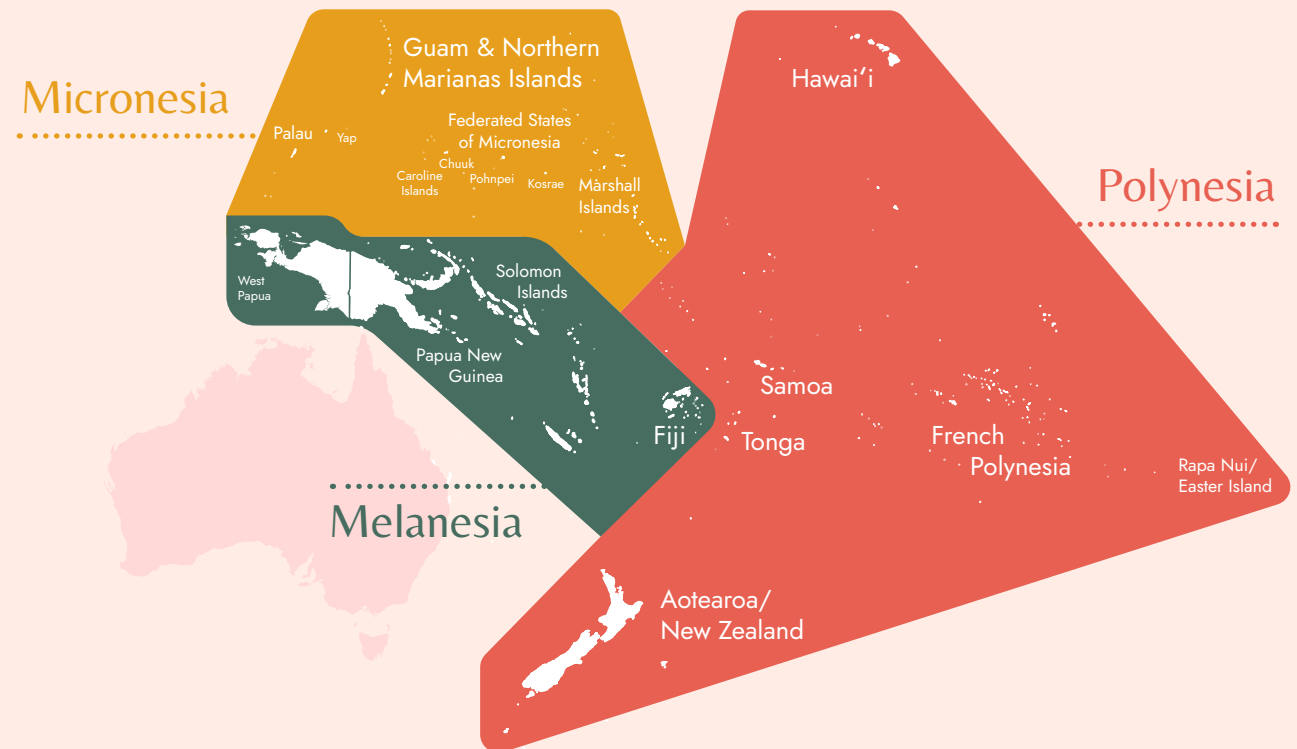Tom Peterson
Kristen Rohde
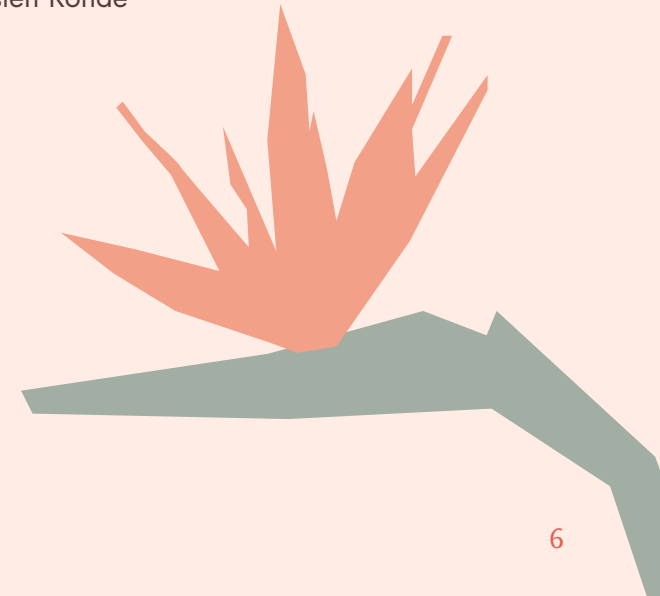
Introduction

Introduction

A Brief History

Pacific Islanders are indigenous to Oceania. Oceania is made up of three regions: Melanesia, Micronesia, and Polynesia - all of which are situated in the largest water mass (the Pacific Ocean) on the planet. Like its waters, Pacific Islanders hold rich and vast experiences rooted in culture, language, and a deep kinship with our ancestral lands.

Between 2000 and 2010, the Pacific Islander population was the fastest growing racial or ethnic group in the United States (US).[1] Population estimates from the 2019 US Census' American Community Survey[2] indicate that Oregon is one of ten states in the US with the largest Pacific Islander populations (Hawaii, California, Washington, Texas, Utah, Florida, Nevada, New York, and Arizona are the others in the top ten). The estimated size of the Pacific Islander population will undoubtedly increase again with the 2020 Census results, being one of several racial and ethnic groups that were a specific focus of the US Census' expanded communications campaign[3] to encourage participation in the 2020 decennial Census.

OCEANIA

Micronesia
Polynesia
Melanesia

Guam & Northern Marianas Islands
Palau · Yap
Federated States of Micronesia
Caroline Islands · Chuuk · Pohnpei · Kosrae · Marshall Islands
West Papua
Solomon Islands
Papua New Guinea
Fiji
Tonga
Samoa
French Polynesia
Hawai'i
Rapa Nui/ Easter Island
Aotearoa/ New Zealand

Despite the increasing size of the population in Oregon there is a significant lack of disaggregated data on Pacific Islander communities. Even basic information, such as an accurate and community-verified count of Pacific Islander individuals throughout the state, is lacking.[4] Pacific Islanders are also underrepresented in data from state and local public health surveys like the Behavioral Risk Factor Surveillance System (BRFSS). The

BRFSS is the largest, continuously conducted telephone health survey in the world and is a collaborative project between the Centers for Disease Control and Prevention (CDC) and US states and territories. In Oregon, the BRFSS is coordinated and administered by the Oregon Health Authority's Public Health Division.

[1] 2010 Census Brief, The Native Hawaiian and Other Pacific Islander Population: 2010
[2] 2019 US Census' American Community Survey
[3] US Census Bureau, 'Census Bureau Reaches Native Hawaiians and Pacific Islanders Through Music'
[4] Coalition of Communities of Color, 'The Asian & Pacific Islander Community in Multnomah County: An Unsettling Profile'

Introduction
Data Challenges

Photo credit: Oregon Pacific Islander Coalition

The BRFSS aims to collect state-specific data on preventive health practices and risk behaviors that are linked to chronic diseases, injuries, and preventable infectious diseases in the adult population. Oregon's state and local health departments rely heavily on the BRFSS for population health data. Oregon Health Authority's Public Health Division conducts over 8,000 BRFSS telephone surveys every year with a random sample of adults as well as a racial and ethnic oversample every 4-6 years to increase the number of BRFSS respondents from Oregon's Black and African American communities, American Indian and Alaska Native communities, Asian communities, and Pacific Islander communities. Oregon's state and local health departments depend on BRFSS data for a variety of purposes, including decisions about where to target and fund services, priorities for seeking grant funding, which health issues to address, what legislation to propose, and how to measure progress toward health objectives.

The BRFSS faces numerous challenges in terms of data quality, validity, reliability, and sustainability. For example, the BRFSS survey has become very long to accommodate demands

for additional questions because it serves as the primary source of data on many health indicators in Oregon. With the added length, Pacific Islander respondents -- who have never benefited from their participation -- are met with interviewers who move quickly through questions in order to ensure completion. These interviewers often lack the relationships, cultural competency, language abilities and trauma-informed practice necessary to engage Pacific Islanders. The BRFSS survey covers sensitive topics (e.g., adverse childhood experiences or ACEs, food insecurity, and housing stability), and rushing through them - let alone discussing such private information at all - could be traumatizing for some respondents. The topic areas covered by the BRFSS have never been informed through community engagement and often fail to capture the health priorities of specific communities.

Given these limitations, it is not surprising that Pacific Islanders are severely underrepresented in the BRFSS - more so than any other racial or ethnic group in Oregon. To illustrate, the last racial and ethnic oversample conducted for the Oregon BRFSS successfully recruited

only 106 Pacific Islander respondents over the course of 3 years. Clearly, the BRFSS' general approach, methods, uninformed topic areas, and lack of diverse languages are particularly consequential in Pacific Islander communities. For these reasons, Oregon's Pacific Islander communities partnered with Program Design and Evaluation Services (PDES) and the Oregon Health Authority's Public Health Division on Pacific Islander Data Modernization (PIDM). PIDM represents one component of work funded through the Oregon Legislature's investment in Public Health Modernization focused on updating Oregon's adult survey systems to address the challenges mentioned above.

Introduction
Previous Works

PIDM builds off of previous efforts to expand data collection on Pacific Islanders in Oregon: Multnomah County's Pacific Islander Data Project and Community Counts. The Pacific Islander Data Project (PIDP) launched in November 2018 with five objectives in mind:

1 Understand Tradition

Develop an understanding of the culturally-based traditions and strengths that support the health and well-being of Pacific Islanders in Multnomah County.

2 Understand Health

Understand major health issues and barriers to healthcare access experienced by the Pacific Islander community.

3 Increase PI Data

Increase the availability of data on the health of the Pacific Islander community at the granular level (i.e., disaggregated from data on Asian communities).

4 Build Capacity

Build capacity in the Pacific Islander community in understanding data about the community and to design and participate in community-based participatory action research.

5 Strengthen Partnerships

Strengthen partnerships between the Multnomah County Health Department (MCHD) and Pacific Islander-serving community-based organizations.

PIDP resulted in five community compasses (brief reports) focused on: Sexual Health and Gender Identity, Parent and Child Health, Mental Health, Climate Change and Chronic Disease, and Nutrition. Each of these topic areas were selected, co-facilitated, and validated by the community. Embedded in each compass are recommendations on how to best navigate addressing the complex health status of Pacific Islanders. These recommendations named that achieving health equity for Pacific Islanders requires thoughtful disaggregation of data, and

robust engagement of Pacific Islander leadership in research.

Community Counts was a partnership between Oregon's Chuukese community and PDES, and was funded by the Oregon Health Authority's Office of Equity and Inclusion and the Public Health Division. Community Counts tested a respondent-driven sampling approach to administering a BRFSS-type survey and successfully recruited 120 participants, nearly all of whom completed the interview for the survey

in Chuukese. Data collected from the surveys and during follow-up listening sessions emphasized many community strengths, a few challenges, essential guidance for advancing Pacific Islanders' health and well-being, and recommendations for improving public health surveys for Pacific Islanders. Chief among these recommendations was to engage communities in the processes of leading the research effort including designing methods, developing participant recruitment strategies, creating data collection tools, and interpreting and reporting findings.

Introduction

Community-Led Research Model

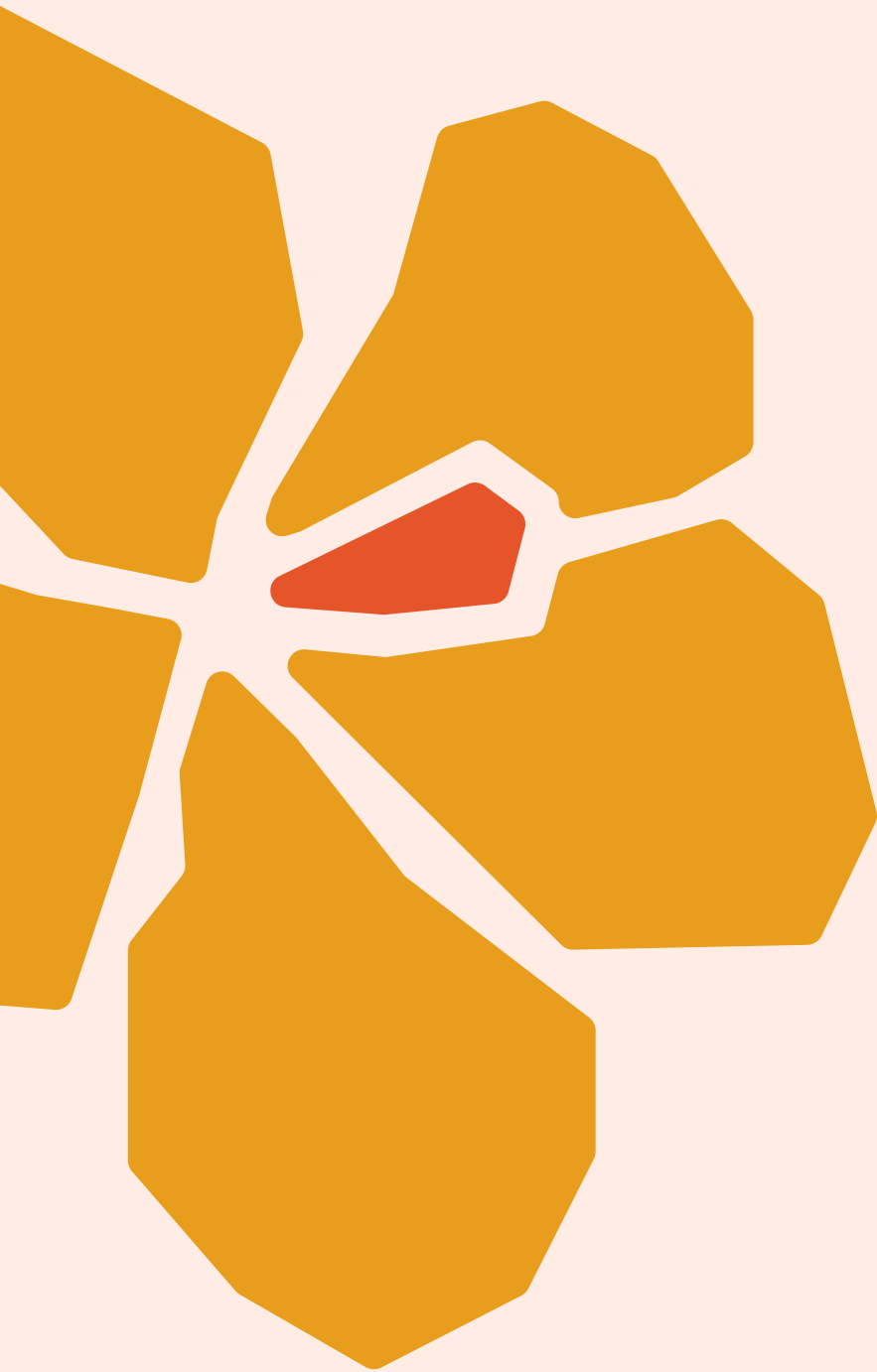*Photo credit: Pacific Islander Data Modernization*

The lessons from these previous bodies of work helped develop PIDM's community-led research model. The community-led research model is rooted in decolonization. Decolonization is the act of dismantling the settler-colonial logic that not only drives, but also justifies the erasure of Pacific Islanders. This erasure happens through complex systems of alienation, coercion, and exploitation. More importantly, decolonization centers community healing and an equitable distribution of power. This translates to cultivating trusting relationships, and recognizing Pacific Islanders' rights to self-determining what is required to create healthy communities for Pacific Islanders.

Through this approach, the Oregon Pacific Islander Coalition required the Oregon Health Authority's Public Health Division to enter a Data Sovereignty Agreement (DSA). In this case, the DSA outlines the power structure between the sponsoring research institution, the researchers,

and the community being researched. The DSA prevents researchers and institutions from extracting data from communities and claiming the research solely as their own, which is a common practice of settler-colonial logic. Instead, the community is the primary beneficiary of the work, the final decision-maker, and an owner and author of the resulting research. This means that the community:

1 Served as the research experts, engagement experts, language experts, and writers;

2 Was properly compensated for the expertise that they provided at every stage of the project; and

3 Utilized the Oregon Health Authority's Public Health Division as a technical assistance resource rather than as a governing body for the work.

The DSA also created the conditions that allowed this project to utilize a Pacific Islander framework on community health, rather than one predetermined by existing government surveys (such as the BRFSS) that fail to capture the community's unique relationship to health and health equity. This resulted in the development of the Pacific Islander Health, Equity, and Liberation (PI HEAL) Assessment - the primary data collection tool used in this project. The tool honors Pacific Islander ways of knowing and being, including our relational worldview, holistic approach to health, and collectivist cultures.

Methods

Community Leadership

Community leadership is the core to the success of this work. There were three main levels of engaging Pacific Islander leadership:

1 Core Research Team

The Core Research Team was responsible for the overall approach, timeline, budget, community engagement, data collection, and data analysis for the project. Three out of five of the Core Research Team members are public health practitioners/researchers with deep ties to Oceania.

2 Community Based Organizations

Community-Based Organizations (CBOs) served as high-level advisors on the project, workshop hosts, and outreach experts. All CBOs involved are led by and provide service to Pacific Islanders.

3 Community Research Workers

Community Research Workers (CRWs) co-developed and co-facilitated the data workshops that provided the robust qualitative data included in this work, and supported overall data analysis. All but one CRW identified as Pacific Islander.

Through these avenues, Pacific Islanders served as the subject matter experts leading the dialogue (and thus, data collection) with other Pacific Islanders on what practices, opportunities, and challenges exist for Pacific Islanders when it comes to health and healing.

PI HEAL Assessment

The Pacific Islander Health, Equity, and Liberation (PI HEAL) Assessment was developed to tell the story of Pacific Islander health and healing. It draws inspiration from Prevention Institute's THRIVE (Tool for Health & Resilience in Vulnerable Environments) framework to assess different community health factors significant to Pacific Islanders. The assessment is composed of four overarching categories and their respective community health factors:

PEOPLE
Community Connections, Care for Community, and Community Values

PLACE
Housing, Food, Access to Land, Getting Around, and Cultural Centers

OPPORTUNITY
Living Wages, Local Wealth, Education, and Information

HEALING
Self Determination, Decolonization, Spiritual Health, and Healthcare

Knowing that the core value of Pacific Islanders is caring for the larger community*, rather than the individual alone, participants were asked to rate each of the community factors by selecting an option on our "fish" scale that best represents how accessible and abundant this factor is to Pacific Islanders in Oregon. For example:

*Participants identified "the larger community" as other Pacific Islanders in Oregon, extended relatives, people they go to church with, or their neighbors

LESS ABUNDANT · MORE ABUNDANT

BONE FISH	ONE LITTLE FISH	ONE LARGE FISH	TWO FISH	THREE FISH
Myself, my family, and my community do not have this	This is something I have personally, but is not something that my family or community have	This is something I have and my family have, but not my community	This is something I have, my family have, and some of my community have	This is something I have, my family have, and my community have

An example of the PI HEAL Assessment with full descriptions of each community health factor appears in the Appendix.

Methods

Data Collection

All PI HEAL Assessment data was collected through an online version of the assessment. The English, ʻŌlelo Hawaiʻi, Pohnpeian, and Tongan versions of the assessment were accessible through the Pacific Islander HEAL website. Respondents who took the online survey, but did not attend a workshop, were entered into a raffle to win one of five $100 gift cards.

The Core Research Team also partnered with the Pacific Islander-led and serving CBOs to host five data workshops. Workshops were co-designed and co-facilitated by a Workshop Team. Each Workshop Team had two CRWs, at least one CBO representative, and at least one

Core Researcher. The Data Workshops served two purposes:

1 Collect meaningful qualitative data to contextualize online assessment results.

2 Build/lift up data and research capacity within the Pacific Islander community.

The workshops made time for each participant to respond to the PI HEAL Assessment on their own. Afterwards, participants were broken up into small group discussions to share their initial feedback on the assessment and to explain why they responded the way they did. Participants

were brought back together as a large group to debrief and close out the workshop. Workshop participants were compensated $75 in recognition of the time, energy, and wisdom they provided.
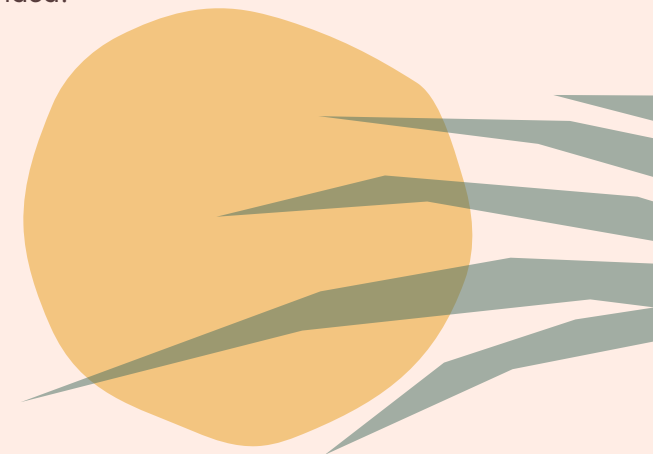
Methods
Data Analysis

Responses to the PI HEAL Assessment were analyzed in aggregate using IBM SPSS Statistics version 24. Response frequencies and percentages were calculated for each assessment question. Means and standard deviations were computed where possible and appropriate (e.g., average age of respondents). We intended to conduct a more detailed analysis by subgroups of interest (e.g., by Pacific Islander ethnic identity, age, gender identity, county, and disability status, etc.), however we were unable to do so given the small numbers of responses in these subgroups. As data collection efforts further develop with Pacific Islander communities in Oregon, we hope that future iterations of this work will allow for analyses by subgroups.

Discussions from the Data Workshops were recorded by notetakers and via Zoom recording. CRWs and Core Research Team members conducted thematic coding of the discussion data from individual workshops, utilizing the PI HEAL community health factors as the primary codes to which the data was organized. Additional categories such as feedback on the assessment, quality of the workshop, and recommendations to further strengthen the work were included. The CRWs and Core Researchers across all workshop teams then co-developed causal diagrams to thread together a narrative for how the community health factors are intrinsically connected to the overall health and well-being of the Pacific Islander community.

Results

Characteristics of Respondents

Characteristics of Respondents

Findings from the PI HEAL Assessment and Data Workshops are presented in the charts, tables, and text below. Responses to the assessment are presented in raw, unweighted form. Response categories may not total 100% due to rounding and because participants could select more than one response on certain questions (e.g., when reporting racial and ethnic identities).

Some assessment results cannot be reported when counts are low to protect the privacy and anonymity of community members. In addition, some response categories are combined to maintain privacy. For example, the response options of "Don't know" and "Do not want to answer" are sometimes presented in combination. Data is presented for all available response categories whenever possible.

Community members had the option of skipping questions they did not want to answer. For this reason, the number of responses varied by question.

Whose voices are present?

In all, 136 Pacific Islander community members responded to the PI HEAL Assessment. Ninety-nine community members submitted complete responses and 37 answered some but not all of the questions. Six community members responded to the Tongan assessment and 130 responded to the English assessment.

This section describes the voices that are present in the responses, including how they reported race, ethnicity, language, disability, gender identity, sexual orientation, age, and where they live in Oregon/SW Washington. We also report the number of community members who attended a PI HEAL Data Workshop, described in the previous section.

Race & Ethnicity

Ethnicity	Count
Tongan	40
Native Hawaiian/Kanaka Maoli	37
CHamoru/Chamorro	23
Samoan	20
Marshallese	11
Chuukese	7
Fijian	7
Pohnpeian	4
Pingelapese	3
Carolinian	2
Maori	2
Palauan	2
Refaluwasch	2
Yapese	2
Sonsorolese	2
Solomon Islands	1
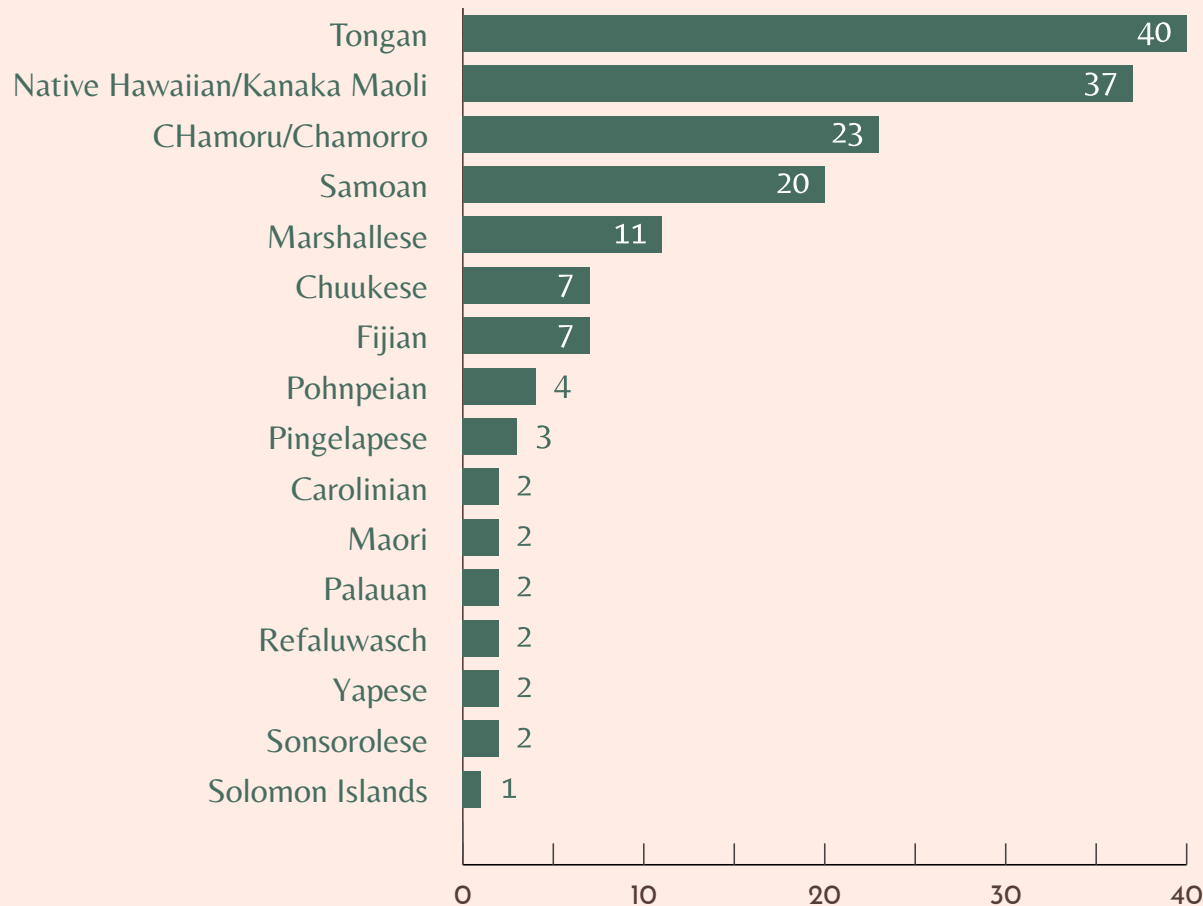
PACIFIC ISLANDER ETHNIC IDENTITY

The PI HEAL Assessment was intended for Pacific Islander community members, therefore all 136 respondents reported one or more Pacific Islander ethnicities. The chart below displays the different Pacific Islander ethnicities respondents reported either alone or in combination with other Pacific Islander ethnicities or non-Pacific Islander racial and ethnic identities. Overall, community members reported 16 different Pacific Islander ethnic identities representing Polynesia, Micronesia, and Melanesia.

Race & Ethnicity

OTHER RACIAL AND ETHNIC IDENTITIES

PI HEAL Assessment respondents had the opportunity to select multiple racial and ethnic identities to reflect how they identified and how they wanted to be represented in the data. Most PI HEAL respondents reported one primary racial or ethnic identity while 20% said they identified as Biracial or Multiracial or that they had multiple primary racial or ethnic identities. These community members reported a wide variety of racial and ethnic identities in addition to their Pacific Islander identities including: Filipino/a, Chinese, American Indian or Alaska Native, Japanese, South Asian, Asian Indian, Vietnemese, Taiwainese, African American, Mexican, Puerto Rican, North African, Eastern European, and Western European. The number and variety of racial and ethnic identities reported by community members aligns with previous research that Pacific Islanders often report multiple races and/or ethnic identities– sometimes more than any other racial or ethnic group.

PI HEAL respondents were also invited to describe their racial or ethnic identity using their own words. Below are a few example responses that further demonstrate the breadth of Pacific Islander community members' racial and ethnic identities:

"I am multiple ethnicity, but I identify as Tongan American because that is the cultural background I grew up in."

"Micronesian –> Marshall Islands –> Mokauleej Clan."

"I am multicultural, but I identify as Tongan."

"Native Hawaiian/Otoe Missouria Tribe of Oklahoma."

"The flowering of colonizer and colonized roots."

RACIAL & ETHNIC IDENTITY

Pie chart:
- 76.5%
- 15.2%
- 5.3%
- 3%

Legend:
- One primary racial/ethnic identity
- Biracial or Multiracial
- Multiple primary racial/ethnic identities
- Don't know/Don't want to answer
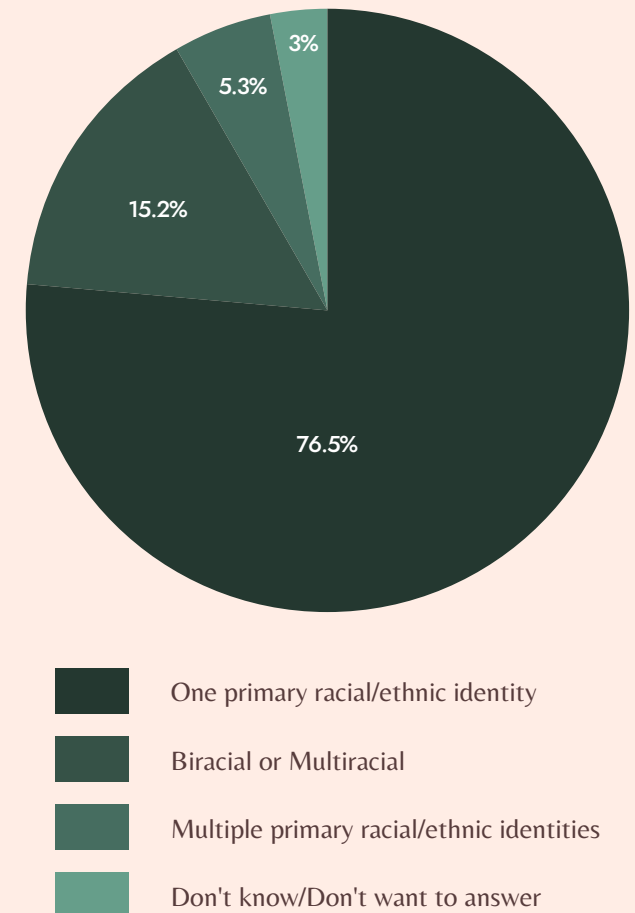
Language

The PI HEAL Assessment asked community members about their language preferences in two questions: "In what language would you like us to speak with you?" and "In what language would you like us to write to you?" The majority said they preferred English for both speaking (86%) and writing (85%). Several said they prefer to speak and write both in English and one or more Pacific Islander languages (7%), and a few said they preferred only Pacific Islander languages for speaking (7%) and writing (6%). The Pacific Islander languages community members

reported speaking and writing included CHamoru, Chuukese, Marshallese, ʻŌlelo Hawaiʻi, Samoan, and Tongan.

Community members were also asked how well they speak English. The chart below shows that the majority said they speak English "very well" or "well," and a few said "not well."

PROFICIENCY IN SPOKEN ENGLISH

3%

4%

28%

66%

- Very well
- Well
- Not well
- Not at all
- Did not answer

Respondents who said they speak English "not well" were automatically asked a follow up question about whether they would like additional help completing the assessment and/or needed the questions in a different language. No respondents requested additional help, and those who needed the assessment in a different language were automatically redirected to the PI HEAL webpage to take the assessment in one of the available Pacific Islander languages.

Results | Characteristics of Respondents

Disability

PI HEAL respondents' disability status was assessed in a series of questions about a variety of disability characteristics. Some disability questions were followed by another question asking the respondent's age when the condition began. Each question about disability characteristics is presented in the table below along with community members' responses.

The data shows that no community members reported being deaf or having serious difficulty hearing. A few community members reported being blind or having serious difficulty seeing, and those who did said their vision troubles began anywhere from 12 to 49 years old. About 6% of respondents reported difficulty walking or climbing stairs that started anywhere from 34 to 60 years old. Very few community members said they have difficulty with self-care like dressing or bathing. About 10% reported having a physical, mental, or emotional condition that limits their activities in some way. Nine percent reported having a physical, mental, or emotional condition that causes serious difficulty

Assessment Question	Yes	No	Don't know/ Don't want to answer	Did not answer
Are you deaf or do you have serious difficulty hearing?	0%	96%	4%	0%
Are you blind or do you have serious difficulty seeing, even when wearing glasses?	3%	92%	0%	5%
Do you have serious difficulty walking or climbing stairs?	6%	89%	0%	5%
Do you have difficulty dressing or bathing?	1%	94%	0%	5%
Does a physical, mental, or emotional condition limit your activities in any way?	10%	82%	3%	4%
Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?	9%	82%	4%	5%
Because of a physical, mental, or emotional condition, do you have serious difficulty doing errands alone such as visiting a doctor's office or shopping?	4%	88%	3%	5%

concentrating, remembering, or making decisions, and about 4% said a physical, mental, or emotional condition causes them serious difficulty running errands alone. Community members who reported these physical, mental, or emotional conditions said they started anywhere from childhood to when they were in their 60s. A few community members said these difficulties began after experiencing a stressful event (e.g., the death of a loved one).

Overall, about 18% of community members who responded to the PI HEAL Assessment reported experiencing one or more disabilities.

Gender Identity

PI HEAL Assessment respondents were asked to report their gender identity. Like the questions about racial and ethnic identity, community members had the opportunity to select as many categories as they wanted in order to fully describe their gender identity. They could also write in a response if none of the options represented their identities as well as any additional information they wanted to include in the description of their gender. The chart below displays the number of community members who selected each category.

Community members also had the opportunity to briefly describe their gender identity in their own words. A few example responses were:

"Gender non-conforming."

"Just a man."

"I'm a female."

"In the process of transitioning."

Category	Value
Woman	90
Man	33
Transgender	3
Non-binary, Agender, and Questioning	5
Feminine-leaning	5
Masculine-leaning	3
Don't know/ Don't want to answer	4
Other gender not listed here	3
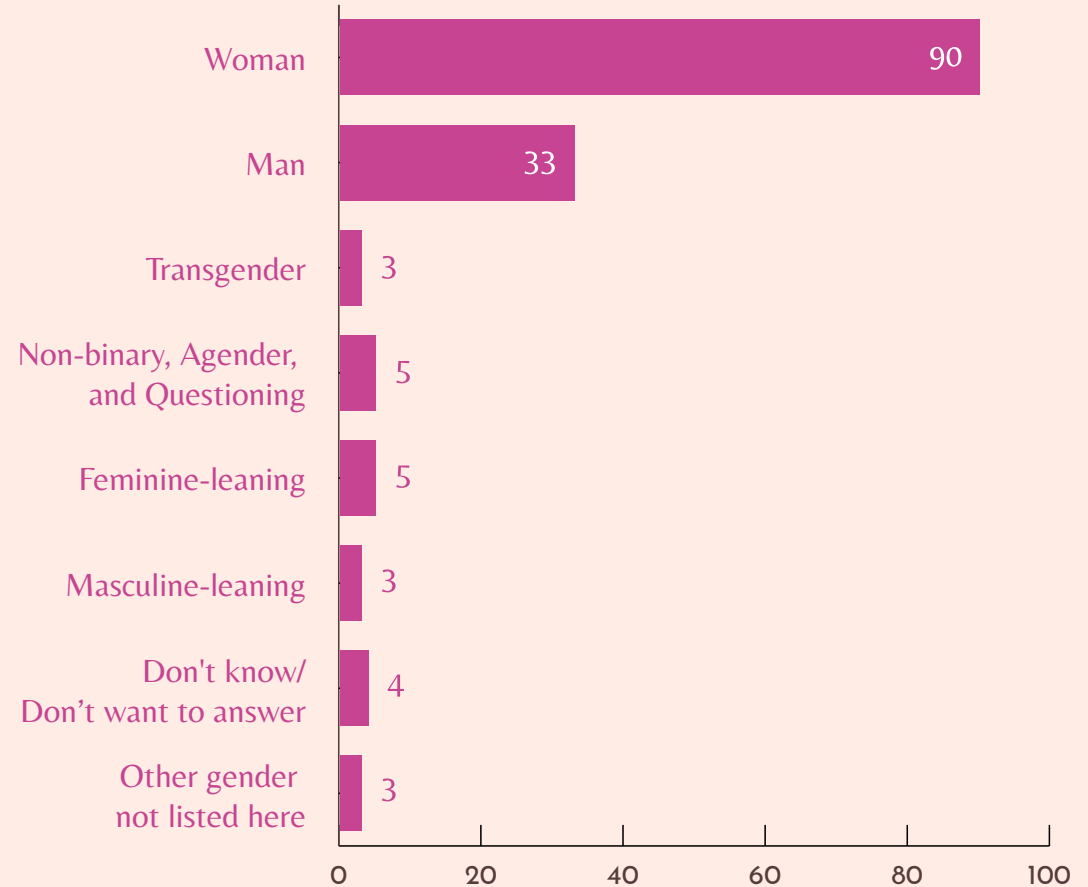
Sexual Orientation
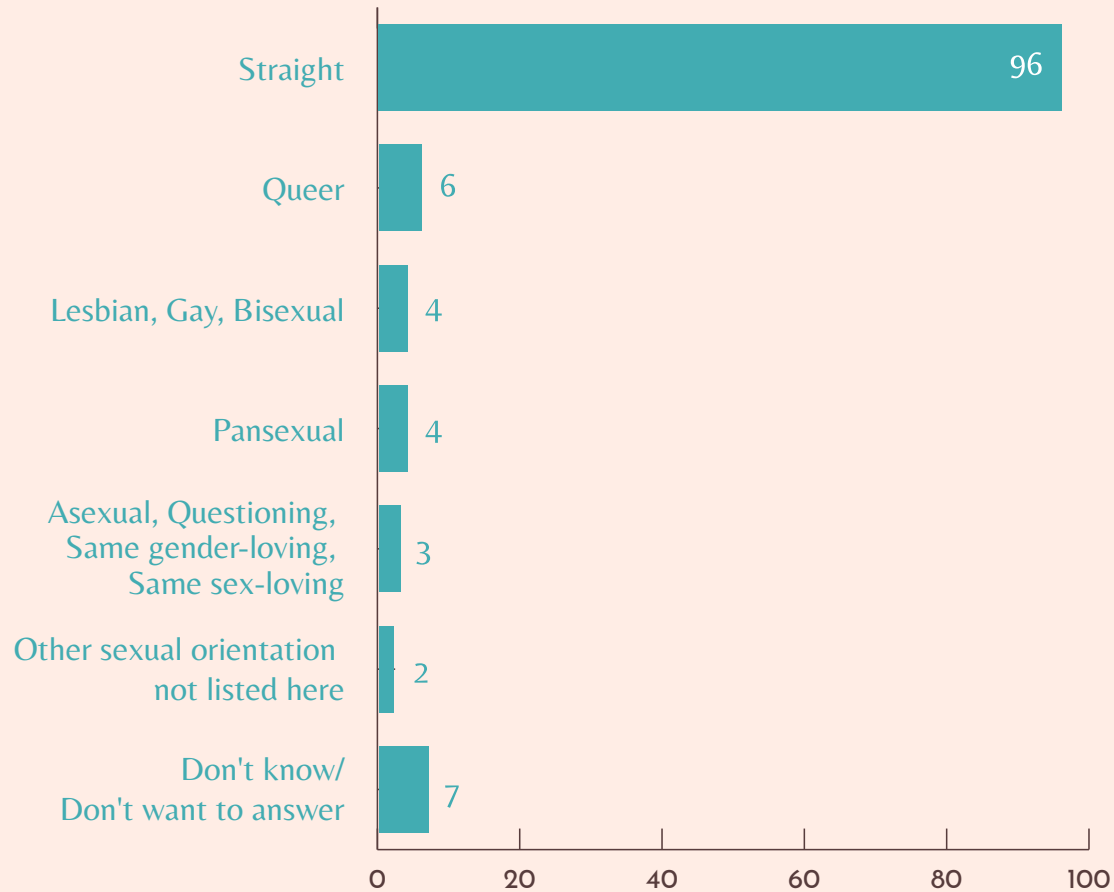
PI HEAL Assessment questions about sexual orientation also provided community members with the option of selecting more than one response. Community members could also describe their sexual orientation in a short response, though few did. The chart below displays the number of community members who selected each category.

Age

Community members who participated in the PI HEAL Assessment varied widely in age. The chart below shows the majority of respondents were between the ages of 26 and 45 years old. Respondents ranged in age from 18 to 74 years old, with an average age of about 39 (standard deviation = 12).

Age group	Count
18-25 years old	15
26-35 years old	40
36-45 years old	41
46-55 years old	16
55 and older	11
Did not answer	13
Don't know/Don't want to answer	7

County

Clackamas
Clark
Coos
Marion
Multnomah
Pierce
Polk
Skamania
Tillamook
Union
Washington
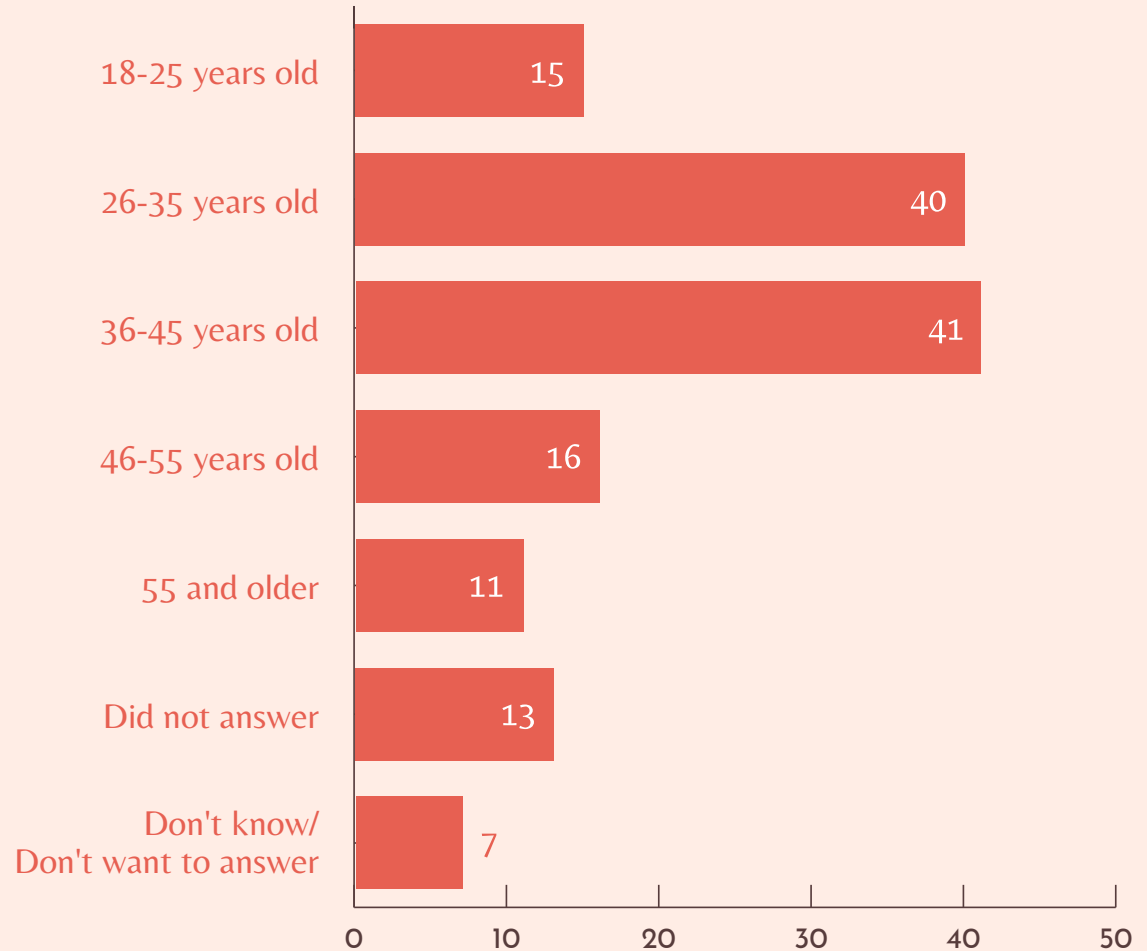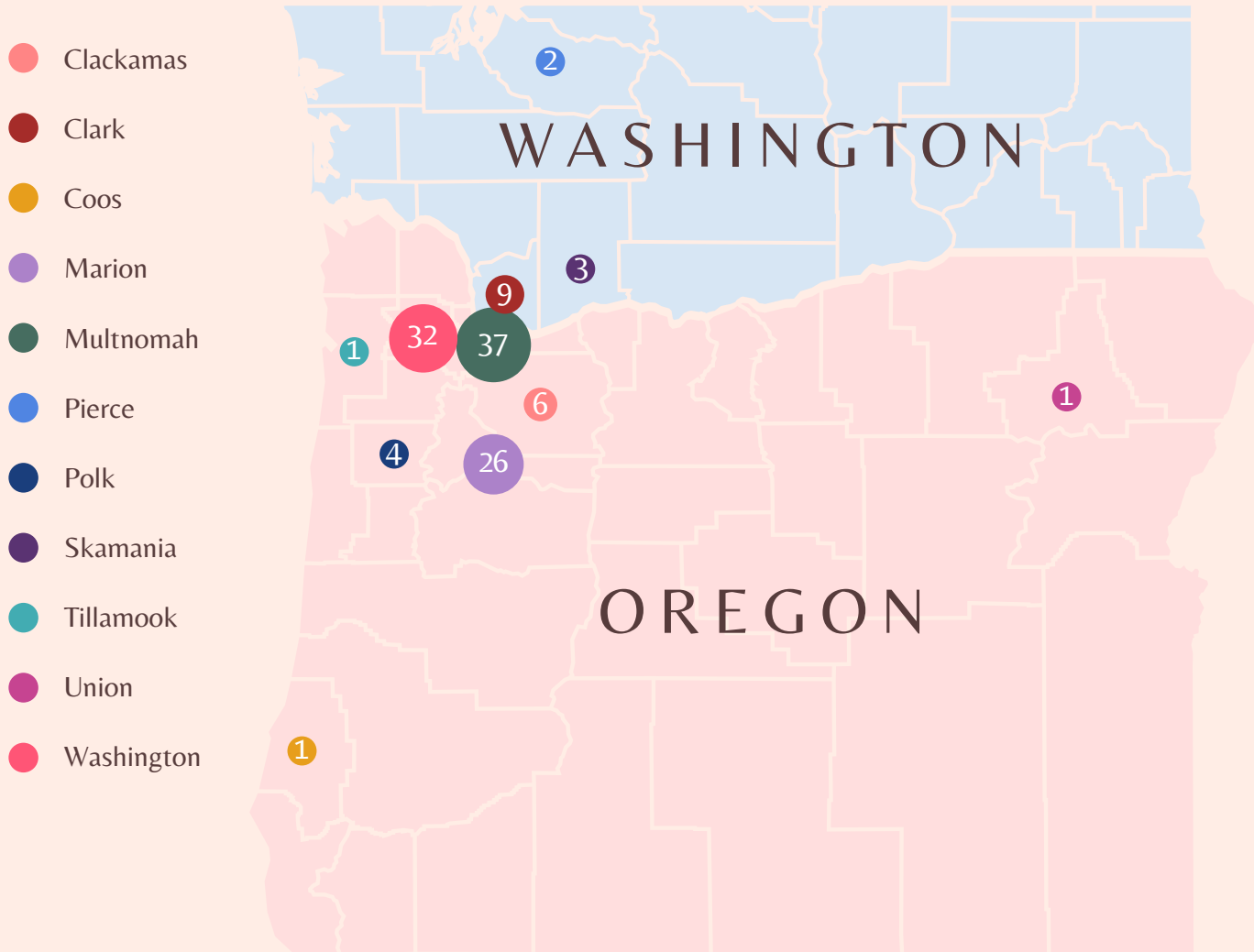
The majority of PI HEAL respondents said they lived in counties in and around the Portland metro area. The map below shows there were more than 30 respondents from Washington county, nearly 40 from Multnomah county, and a few respondents from Clark and Skamania counties in SW Washington. Another large response came from community members living in Marion and Polk counties which cover the Salem metro area. A handful of responses came from more rural counties on the coast (Coos and Tillamook) and in eastern Oregon (Union).

Attendance & Perspectives

PI HEAL WORKSHOP ATTENDANCE

One of the last questions on the PI HEAL Assessment asked respondents whether they attended one of five PI HEAL workshops that were hosted by local Pacific Islander-led community-based organizations. Of those who responded to the question, 57% said they attended a PI HEAL workshop. The remaining 43% did not attend a workshop.

WHAT PACIFIC ISLANDER PERSPECTIVES ARE MISSING?

We are delighted by the number and representation of Pacific Islander community members who responded to the PI HEAL Assessment. We also acknowledge that despite the great response, not all Pacific Islander perspectives are represented in the data. Oceania is vast, with over 30 Pacific Island nations and 20,000 islands. While Pacific Islanders from each ethnographic region -- Melanesia, Micronesia, and Polynesia -- are represented in this data set, better and more equitable representation of all Pacific Islanders is required.

Because of the COVID-19 global pandemic and public health restrictions on in-person gatherings, we were only able to offer the PI HEAL workshops and assessment online. This may have excluded community members who do not have access to a computer or smartphone and those who are not connected to the Internet. CBO partners were provided additional funds to support community members with computing hardware and technical assistance, but community members who are not connected to a CBO likely missed that opportunity. In subsequent years, it will be essential to offer the assessment in multiple modes including online, on paper, and over the phone with a Pacific Islander interviewer.

The fact that we relied on an entirely online survey may have prevented the participation of certain community members who otherwise would have taken part if it had been offered in other formats. This includes but is not limited to Pacific Islander elders, who made up a relatively small percentage of our PI HEAL respondents. The wisdom, experiences, and knowledge of Pacific Islander elders are critical to understanding the community's health and well-being, and we recognize that their perspectives are not fully represented in the data.

Another perspective that is missing is that of Pacific Islanders who do not speak, read, or write in the languages in which the assessment was offered (English, ʻŌlelo Hawaiʻi, Pohnpeian, and Tongan). The assessment was also translated into Marshallese and CHamoru/Chamorro, however we were unable to post the assessment and collect data in these languages within our project time frame. We hope to re-engage our language experts in Chuukese, Kapinga Marangi, Palauan, and Samoan to translate the PI HEAL Assessment into these languages for future work with the community.

While our CBO partners and recruitment strategies successfully recruited a number of Pacific Islanders living outside the Portland metro area, the voices of community members from Oregon's rural areas are mostly lacking. The majority of PI HEAL respondents reported living in the Portland metro area, and many others reported living around the I-5 corridor (i.e., Marion county and the Salem metro area). There are growing Pacific Islander communities in counties in Oregon's Eastern, Southern, and Coastal areas that should have a larger presence in future iterations of this work.

Results

Assessment & Workshop Results

Ratings of Community Health Factors

PEOPLE   PLACE   OPPORTUNITY   HEALING
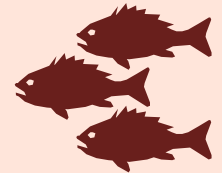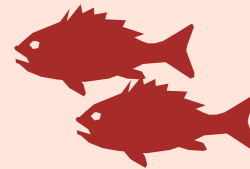
The PI HEAL Assessment asked Pacific Islander community members to rate 16 community health factors based on how accessible and abundant they believe the factor is to Pacific Islanders in Oregon. The sections below present how community members rated each health factor using the PI HEAL Assessment "fish" scale, which allowed respondents to consider accessibility and abundance for themselves, their families, and their community.

Each section of the results is organized by the four PI HEAL Assessment categories: People, Place, Opportunity, and Healing. Under each category is a written summary of the quantitative data and a visual representation of the quantitative data. Each data visual is followed by a qualitative analysis highlighting the written comments in the online assessment and responses when community members were asked "Why did you respond to the assessment the way you did?" during the data workshops. Not all community health factors are individually highlighted due to a lack of response, lack of time to discuss, or discussion of them being rolled into other community health factors.

Community Members in this scenario refer to the workshop participants or online assessment respondents. Community Leaders in this scenario refer specifically to those who identified themselves as members of a community organization or church during the workshops.

People

The People category within the PI HEAL Assessment asked community members to rate the accessibility and abundance of Community Connections, Care for Community, and Community Values. The chart below shows that overall, a little over half of community members reported that Community Connections, Care for Community, and Community Values are abundant and accessible for themselves, their families, and at least some of their broader community.

Community connections can grow the abundance of access to resources or completely dissolve it. Community members frequently commented on the lack of a direct relationship with the state and how reliant they are on church leaders, elders and family members for resources such as access to affordable housing, medical interpretation, or support with health insurance applications. This can be challenging because social hierarchies within the community can limit the few resources that are available. At the same time, the community serves as an irreplaceable resource on healing, cultural preservation, and formation of one's identity. These connections

Low Abundance   High Abundance

Community Connections
10% 11% 24% 32% 24%

Care for Community
21% 14% 13% 34% 18%

Community Connections
11% 12% 21% 37% 21%
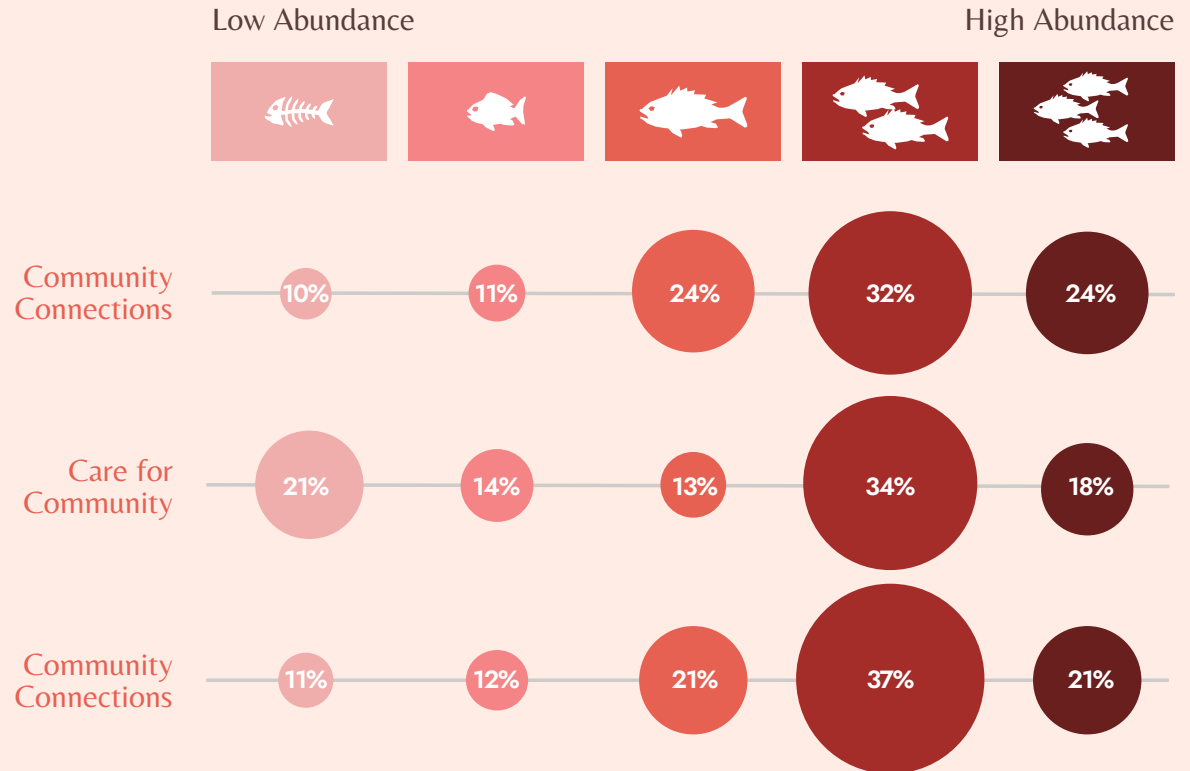
People CONTINUED

are critical on a practical and spiritual level and a core protective factor for Pacific Islanders.

Care for the community often shows up heavily through church involvement, but community members want to see greater Pacific Islander care in other areas, such as political advocacy groups or school-based communities. For example, Marshallese leaders noted that it is hard to have political power when you cannot vote as a COFA Citizen, so greater political advocacy is needed; especially on intergenerational issues such as nuclear testing and Medicaid restoration which greatly impact their health. Community members also shared that supporting each other during difficult times, providing financial support, and coming together for celebrations is core to Pacific Islander cultures but isolation in Oregon presents several barriers that are mentioned throughout this report. Because churches are the primary resource hub in the community, those not linked to a church

are not receiving the support and care that they need.

Making space to talk about intersectionality and how the community values LGBTQIA+ people is important, but still a taboo topic. Some community members were not sure what the acronym stood for, others avoided the discussion, and a few raised that lumping inclusion of LGBTQIA+ people with respect for elders in the same definition felt inappropriate. However, there are also community members who said that the community's values around LGBTQIA+ people, prevalence of anti-Blackness, and the friction between religious customs and cultural customs needs to be challenged. Across these perspectives community members shared that multigenerational conversations need to happen if we want to see shifts in these values. Elders in particular play a huge role in defining social hierarchies and setting the values of the community.

> "We are our own medicine."
>
> - DATA WORKSHOP PARTICIPANT

Place

The Place category asked community members to rate the accessibility and abundance of Housing, Food, Access to Land, Getting Around, and Cultural Centers. Compared to the community health factors in the People category, community members' ratings of health factors in the Place category were a little more varied. About 40% of community members reported that Housing is something that is accessible and abundant for themselves, their families, and at least some of their community. More than half reported the same level of abundance and accessibility for Food. A little less than half reported that Access to Land was something that they have personally, their families have, and at least some community members have. The community health factor of Getting Around received the highest ratings, with nearly 75% of community members reporting that ease of transportation is something that they have personally, their families have, and at least some of their community has. Cultural Centers, however, is something that more than half of community members said is not accessible or abundant for themselves, their families, or their community.

Low Abundance   High Abundance

Housing	22%	14%	25%	31%	8%
Food	18%	11%	18%	38%	15%
Access to land	29%	8%	15%	30%	18%
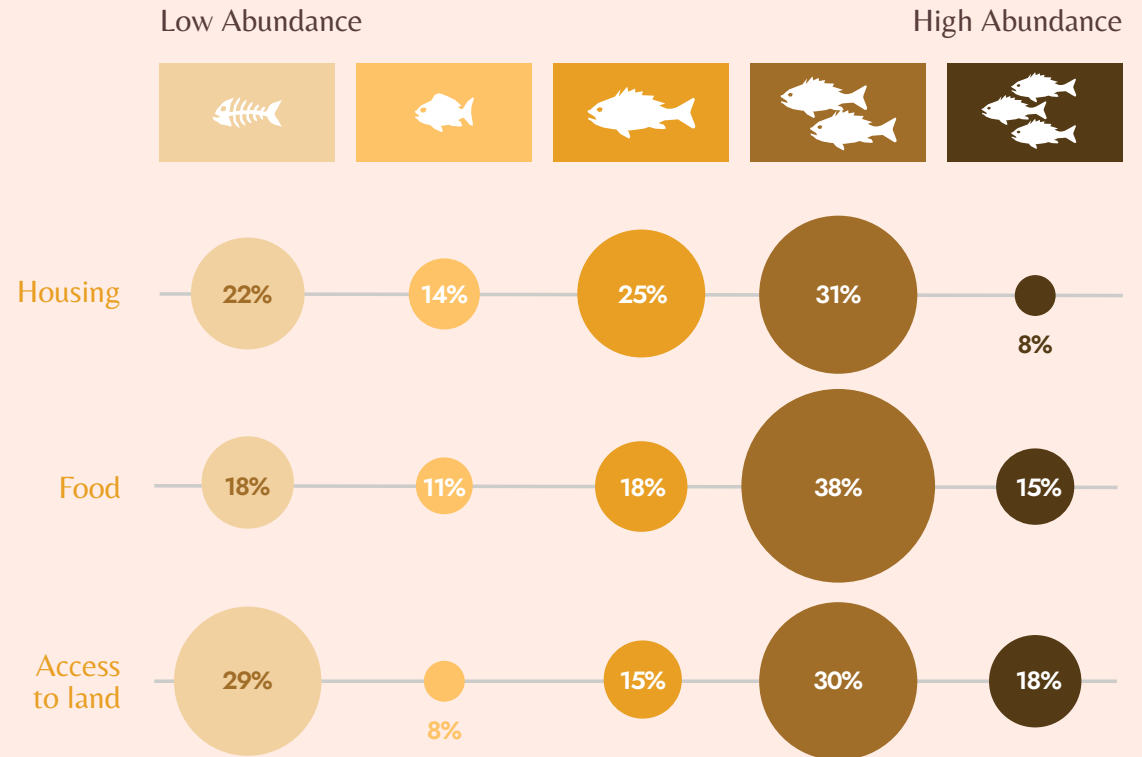
Place CONTINUED

Affordable and quality housing in safe neighborhoods that can host multigenerational and multifamily households is critical and yet extremely difficult to come by. The lack of connection to existing affordable housing resources means the community is reliant upon church or family to access housing. This can be difficult for LGBTQIA+ community members or those not connected to the church. Those who can access the housing resources still have trouble affording what is available due to poor credit histories, challenges providing proof of self-employment income, or lack of a livable income all together. Even when housing is secured, it is hard to maintain. This can be due to high utility bills in the winter, competing financial priorities given the household's limited income, or the risk of getting evicted given the number of people in the home.

Affordable rentals are important, <u>and</u> the community wants to see greater investments and resources put into home ownership. Transitioning to an economic and social environment where home and land ownership is not a cultural norm or financially feasible is hard. An important part of cultural preservation is having land

Low Abundance   High Abundance

Getting around: 9%, 13%, 6%, 39%, 34%

Cultural centers: 56%, 7%, 11%, 18%, 8%
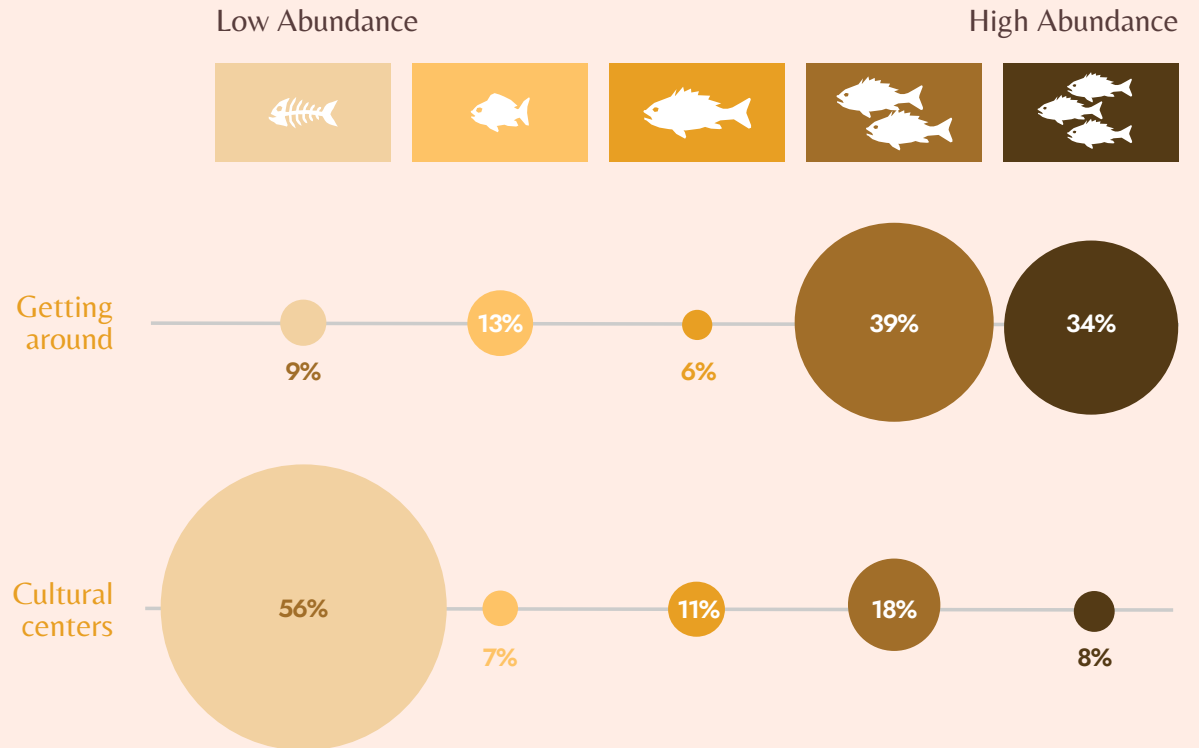
Place CONTINUED

to house your family and grow traditional foods over generations. Yet, many community members feel discouraged because of the lack of affordability or difficulty restoring their credit. Even in situations where money may not be the challenge, community members recall racist mistreatment by realtors, banks, or potential neighbors when purchasing a home.

There is a deep desire to see cultural foods more widely accessible through community gardens, food pantries, and mainstream grocery stores. Cultural foods are hard to come by and typically available through social media, either for purchase or through community food drives. Cultural foods, such as poi, octopus, or pandan, typically have to be shipped in from the islands at heavy cost to community members. This is due to the cost of the product, shipping costs, and minimum purchase requirements to ship overseas. There is also difficulty around not having enough food in the home in general.

Youth in particular are placed in compromising situations because of this. Parents can hold a lot of shame around asking for support to feed their families. The youth's loyalty and respect for their parents prevent them from asking for help, but their role as a caretaker to younger siblings demands that they find food to feed their family. Even when youth make an effort to access food services, they are often denied because they do not have parental permission or are under the age of 18.

Having a physical community space is required to sustain culture and the Pacific Islander community has big visions for what that could look like. The dream for many of the community members and leaders who attended the workshops is to have a Pacific Islander specific cultural center to share ideas, build connections, and host community gatherings in Oregon/ SW Washington. The community wants a space

> ## "Without space, we lose our culture and ability to exercise our customs."
>
> - DATA WORKSHOP PARTICIPANT

where all Pacific Islanders know they can go there to access resources, to receive support, or to just connect with other community members. Community members suggested that the center could be a hub for programs related to cultural education, youth mentorship, culturally specific health services, job readiness training, community gardens, and more. It was also important to community members to recognize that this potential cultural center would be built on Native American land. Community members felt that proper recognition of this required building stronger relationships between Native Americans and Pacific Islanders.
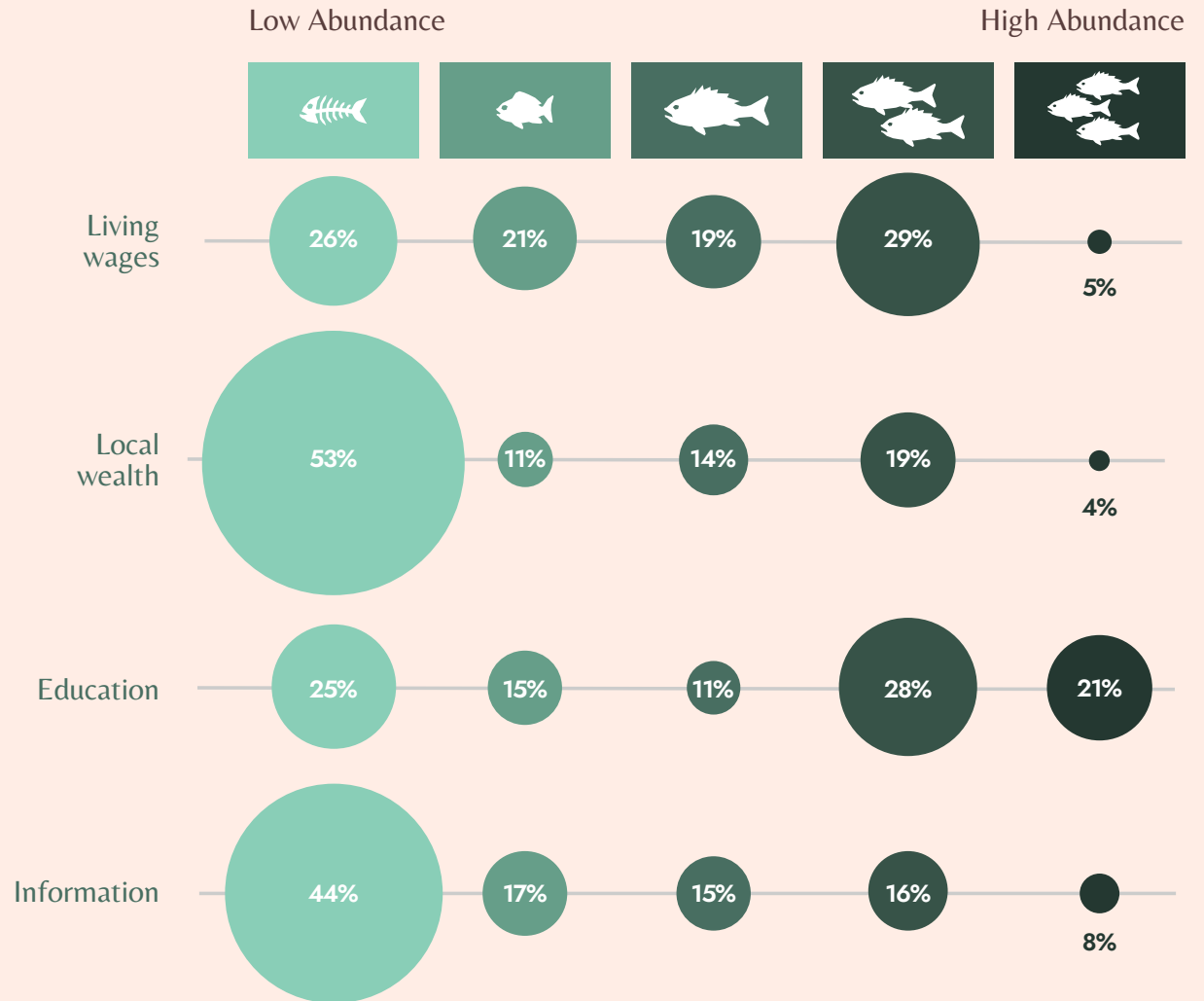
Opportunity

Living Wages, Local Wealth, Education, and Information are the health factors in the Opportunity category. The chart below shows that the factors in the Opportunity category are not as abundant or accessible as the factors associated with People and Place. Only one third of community members reported that Living Wages were abundant and accessible to themselves personally, their families, and at least some of the broader community. Ratings for Local Wealth were somewhat worse, with just over 20% of community members reporting it is accessible and abundant for themselves, their families, and at least some of their community.

In stark contrast, more than half of respondents reported that Local Wealth was not something that they have, their families have, or their communities have. Community members rated Education as something that was slightly more accessible and abundant, with just under 50% reporting it as something they have, their families have, and at least some of the community has.

Finally, only about a quarter of community members reported that Information is something

	Low Abundance				High Abundance
Living wages	26%	21%	19%	29%	5%
Local wealth	53%	11%	14%	19%	4%
Education	25%	15%	11%	28%	21%
Information	44%	17%	15%	16%	8%

Opportunity CONTINUED

they have, their families have, and at least some of the community has. Similar to Local Wealth, 44% of respondents said that Information is something that is lacking for them personally, their families, and their community.

There are a number of challenges when it comes to jobs, wages, and wealth. The resources available do not align with the community's desire to own their own businesses or have career opportunities. Many Pacific Islander families are living paycheck to paycheck and finding livable wages or stabilizing career opportunities are pervasive challenges. With the amount of barriers and challenges to stabilizing finances, community members noted that local wealth and future planning felt so out of reach that it was almost insulting to even include in the PI HEAL assessment. In addition to financial stressors, community members stressed how not being accustomed to the US or utilizing English as their primary language impacts access to steady employment. For example, in Tonga, high school is referred to as college, but this can be difficult to explain or understand when you do not speak English. Some community members are self-employed through construction or landscaping and often provide job opportunities

to family members. However, these businesses need more support in recordkeeping so that employees can provide employment and income history when needed, and so that the business is recognized and validated by employment and business institutions. Yet there is also a fear of disclosing or filing formal paperwork because of community members' immigration statuses.

Pacific Islanders across generations are deeply invested in the future of the youth and want to ensure that their development is rooted in cultural values and educational opportunities. This can be challenging given how individualistic Western education is, the income challenges of their families, and the cultural protocol of their elders. Youth often have to make a choice between providing for their families or investing in their individual education, with many prioritizing the former over the latter. The community wants to see more educational opportunities in youth mentorship, adult education, and English as a Second Language (ESL) for youth. At the same time,

community members do not want this education to conflict with or erase cultural teachings and community values. Proper cultural education for youth is just as important to invest in for the future of the entire community.

Institutions are deeply lacking in providing culturally relevant and accessible information to Pacific Islanders. Information and resources are typically passed on verbally through existing community connections. Many community members need and want help but are not sure where to go or who to receive guidance from. This includes medical translations, general contracting information, affordable housing access, support with taxes, etc. Community leaders expressed their own lack of understanding on what the government is actually able to provide, and emphasized that the community will not read information that is not in their own language.

> "Western knowledge focuses primarily on individual achievement. We believe that our younger generation needs to learn about community values from our elders."
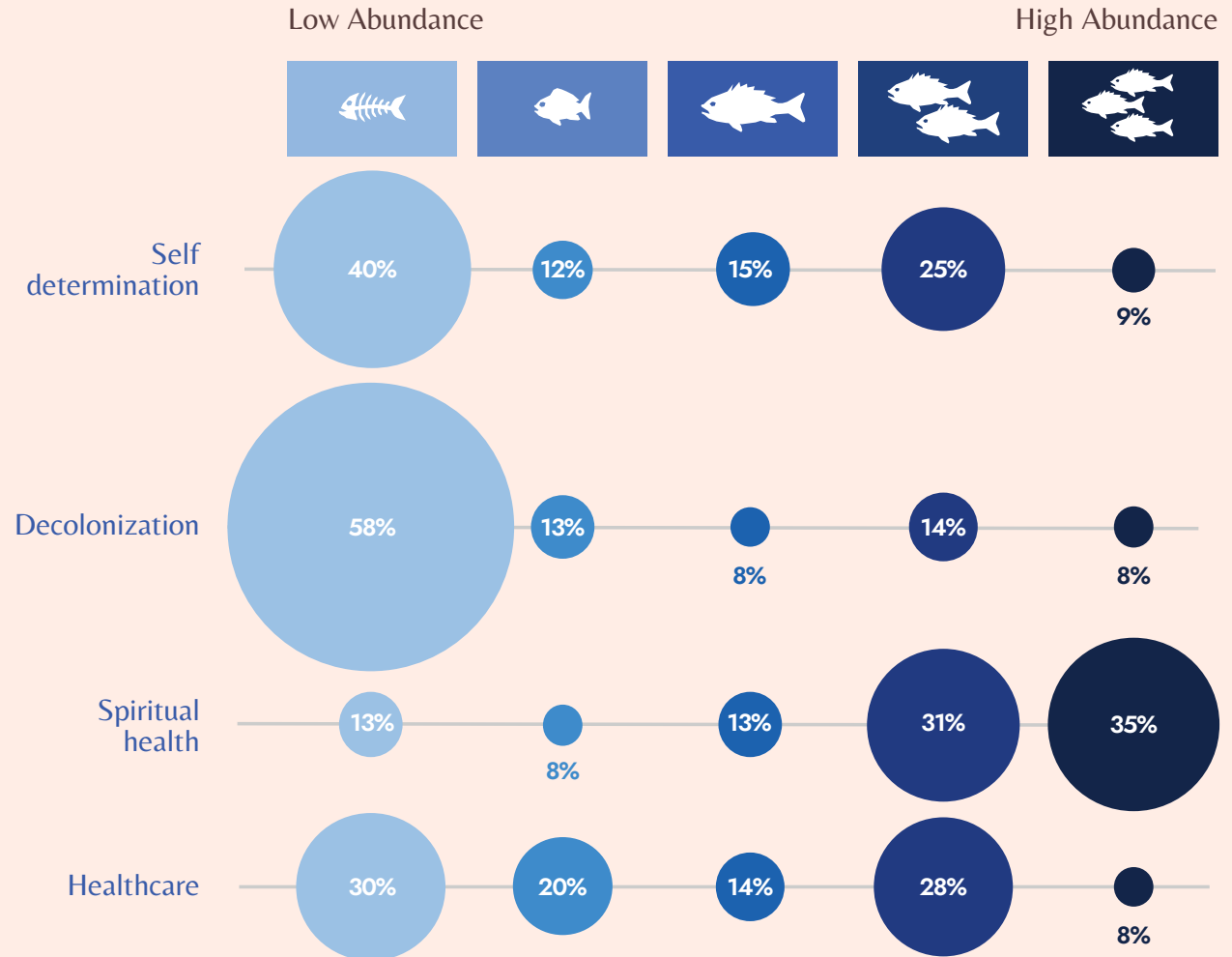> - DATA WORKSHOP PARTICIPANT

Healing

The last category within the PI HEAL Assessment is Healing, which included Self Determination, Decolonization, Spiritual Health, and Healthcare. A little over a third of community members reported that Self Determination is abundant and accessible for themselves, their families, and at least some community members. Forty percent, however, said Self Determination is something that is missing for themselves, their families, and their community. Nearly 60% of respondents rated Decolonization as something that is neither accessible nor abundant for themselves, their families, and their community. Spiritual Health was the most abundant and accessible factor within the Healing category, with about two thirds of community members reporting it as something they have, their families have, and at least some of the community has. Ratings of the Healthcare factor were mixed, with just over a third of community members saying it is something they have, their families have, and at least some of the community has. Another 30% said that Healthcare is lacking entirely for themselves, their family, and their community.

Low Abundance   High Abundance

Self determination: 40% | 12% | 15% | 25% | 9%

Decolonization: 58% | 13% | 8% | 14% | 8%

Spiritual health: 13% | 8% | 13% | 31% | 35%

Healthcare: 30% | 20% | 14% | 28% | 8%

Healing CONTINUED

There needs to be more space to discuss, define, and envision what decolonization and self determination means for Pacific Islanders. Community members gave important feedback on how confusing and loaded the definitions for these two terms were on the PI HEAL Assessment. For example, it was unclear if the decolonization section applied to their experiences in Oregon, or to the lands community members are indigenous to. Some community members noted that while they understood what colonization is, that it was hard to imagine what decolonization could look like. That being said, community members still made the connection between how what happens back home impacts their experiences in Oregon, such as the desecration of Mauna Kea or the 70+ years of exile from Bikini Atoll. Community members also noted the importance of organizing for indigenous sovereignty, while recognizing

that we must support the leadership of those indigenous to Oregon's occupied lands.

The conversations on the "People" category framed community connections as a core piece of spiritual health, and the factors in "Place" as a core barrier to spiritual health. Culturally specific churches are the bastions of community where culture is practiced, language is reinforced, and community and food are shared. But churches are not a safe space for all Pacific Islanders. Thus, it's important to have multiple spaces of healing so that spiritual health is accessible to everyone. Physical space, and its proximity to clean water, are important to practice cultural customs like ceremonies or celebrations.

Access, comfort, and safety within the healthcare system remains a large concern for Pacific

> ## "We are a collectivist culture. We are affected by everything and everyone around us."
> - DATA WORKSHOP PARTICIPANT

Islanders. Community members want to be healthy but feel preventative care opportunities and health insurance access are severely lacking. These barriers have transformed into fatalism in which community members fear going to the doctor out of belief that it will be a bad outcome that they are not able to financially, practically, or emotionally manage with their family responsibilities. There is also a need for medical interpreters who are subject matter experts, can speak the needed languages, will respect the privacy of community members, and are of the same gender. Community members fear that interpreters will spread information given the tight-knight community relationships that exist. Children are often serving as medical interpreters, but can be afraid to ask follow up questions or may not be able to accurately interpret the information between the doctor and the adult.
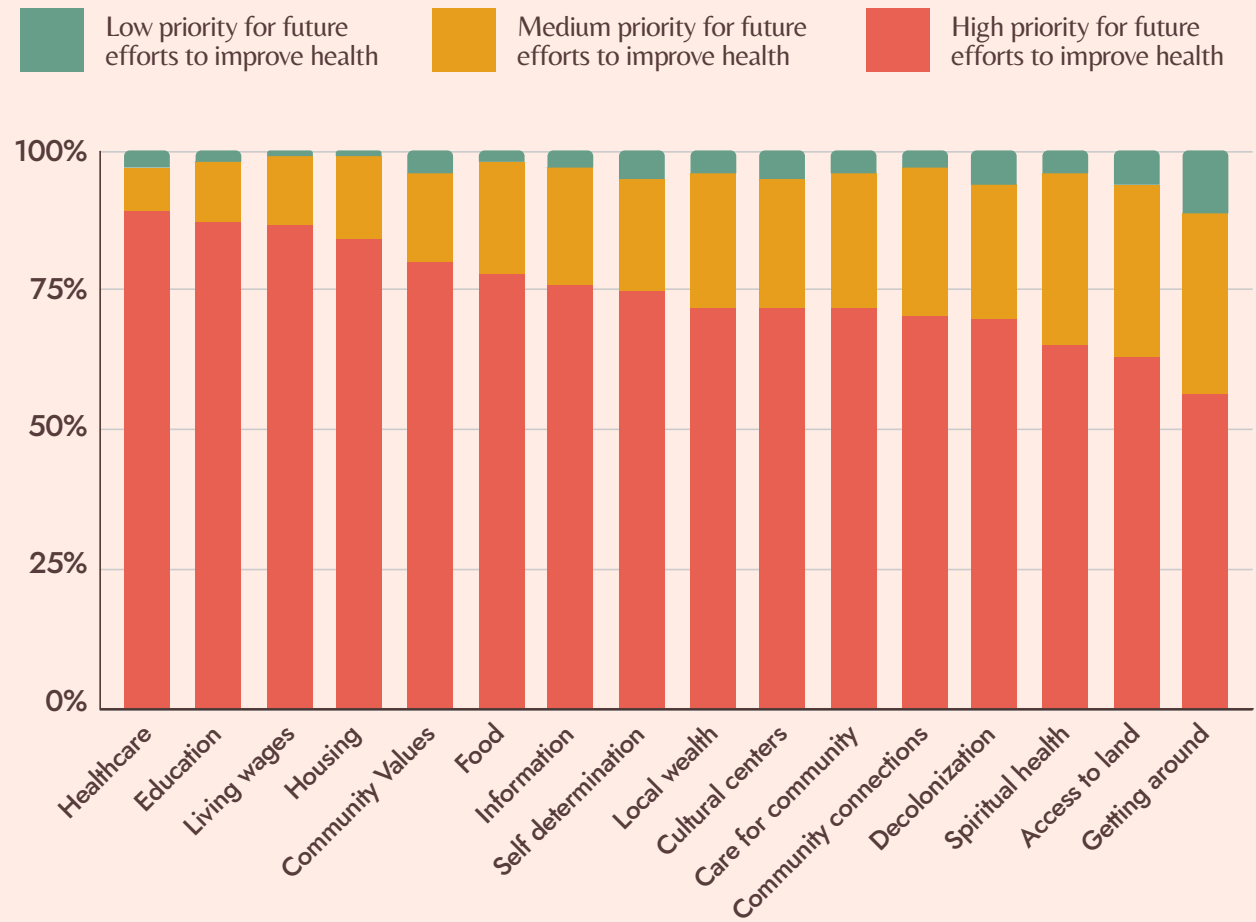
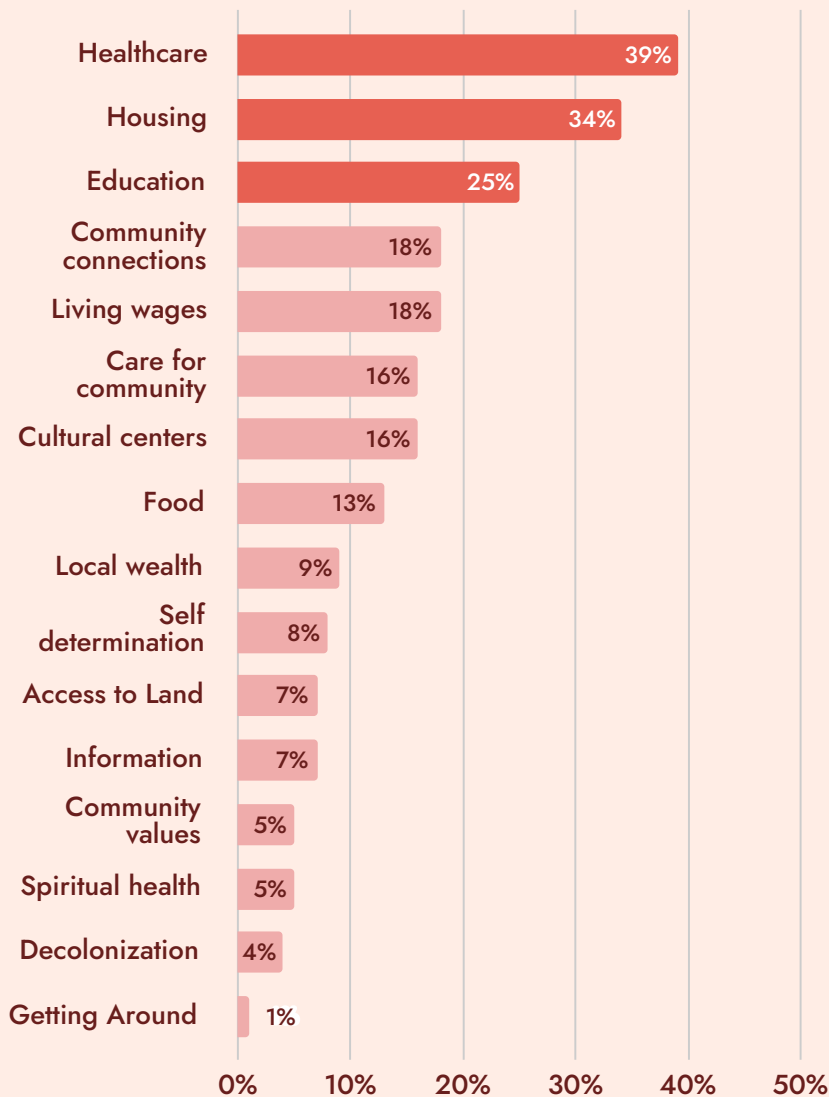# Priority Level of Community Health Factors

After assessing each community health factor, the PI HEAL Assessment asked respondents to rate their importance in terms of any future efforts to improve health in that area. Respondents were asked to rate each factor as either high, medium, or low priority for consideration in future efforts.

The chart below shows that ratings for every health factor overwhelmingly categorized each factor as a high priority for future health improvement efforts. These ratings are no doubt the result of historical disinvestment in Pacific Islander communities and suggest the need for universal efforts to improve all aspects of Pacific Islanders' health and well-being. Defining these efforts requires further collaboration between the Pacific Islander community and the agencies that drive these structural inequities.

Legend:
- Low priority for future efforts to improve health
- Medium priority for future efforts to improve health
- High priority for future efforts to improve health

Top Three Community Health Factors

Top Three Community Health Factors

Factor	Percentage
Healthcare	39%
Housing	34%
Education	25%
Community connections	18%
Living wages	18%
Care for community	16%
Cultural centers	16%
Food	13%
Local wealth	9%
Self determination	8%
Access to Land	7%
Information	7%
Community values	5%
Spiritual health	5%
Decolonization	4%
Getting Around	1%

As a final step, PI HEAL Assessment respondents were asked to select the top three community health factors they felt Pacific Islanders should focus on improving first. The chart below shows the percentage of community members who chose each health factor for one of their top three priorities, listed from factors that received the most votes to those that received the fewest votes. Healthcare, Housing, and Education received the most votes for top three priority, followed by Community Connections, Living Wages, Care for Community, and Cultural Centers.

Community Connections and Care for Community were selected as top priorities, despite both factors being rated as highly accessible and abundant by more than half of community members who responded to the PI HEAL Assessment. This confirms the importance of centering the community in Pacific Islanders' health and overall wellbeing.

Reflections

Reflections

This section serves as a series of high-level reflections based on the core research team's experience with project implementation and the feedback they received during the data workshops.

Capacity building

The community, and State and local public health departments, must continue to invest robust resources for equitable implementation and engagement in this research. Addressing historical inequities requires that every facet of this project - from project management, to compensation disbursement, to supporting the development of community members involved - have the people and funding to power it. In this scenario, our researchers and cultural advisors did not have the capacity to adequately or equitably implement all facets of this project. For example: the project manager also served as a researcher, cultural advisor, supervisor for community researcher workers, and supported individual community members with technology access. While each role was important to the implementation of the project, they cannot all realistically be addressed by one person.

Language expertise

The vast linguistic needs Pacific Islanders require greater staffing and a larger portion of the budget. Conducting this research in non-English languages requires that we resource the work in the way English-versions are resourced. We must move away from believing that a simple translation of the research from English to a Pacific Islander language and vice versa will be adequate. Non-English versions of this research require the leadership of subject matter experts in that language from the very beginning, as well as robust community validation sessions to finalize materials. The absence of this puts the integrity of the research and data at risk.

Reflections CONTINUED

Making the assessment digestible

While the PI HEAL Assessment was well received and appreciated by the community, it is necessary to continue to simplify the language to increase accessibility and strengthen the data. Community members requested that assessment definitions be broken up and written into plain language. Community members also suggested developing rating scale visuals specific to each Pacific Islander culture (not all liked the fish!) and including additional rating scale options. For example: some health factors were accessible to the broader Pacific Islander community, but not the individual answering and there were no rating scale options to express that.

Deepening engagement

Pacific Islanders are ready to engage in research and do a deeper dive on this work. It's important to have a youth and elder specific components to the work given their lack of participation in this iteration, and the community's values on multigenerational wisdom. It's also important to emphasize that the Pacific Islander community is not a monolith and that there needs to be deeper engagement of each Pacific Islander community, deeper investigation of how these community health factors are impacting individuals and households, and more intersectional analyses that consider geography, race, ethnicity, gender, sexuality, language, age, ability, and more.
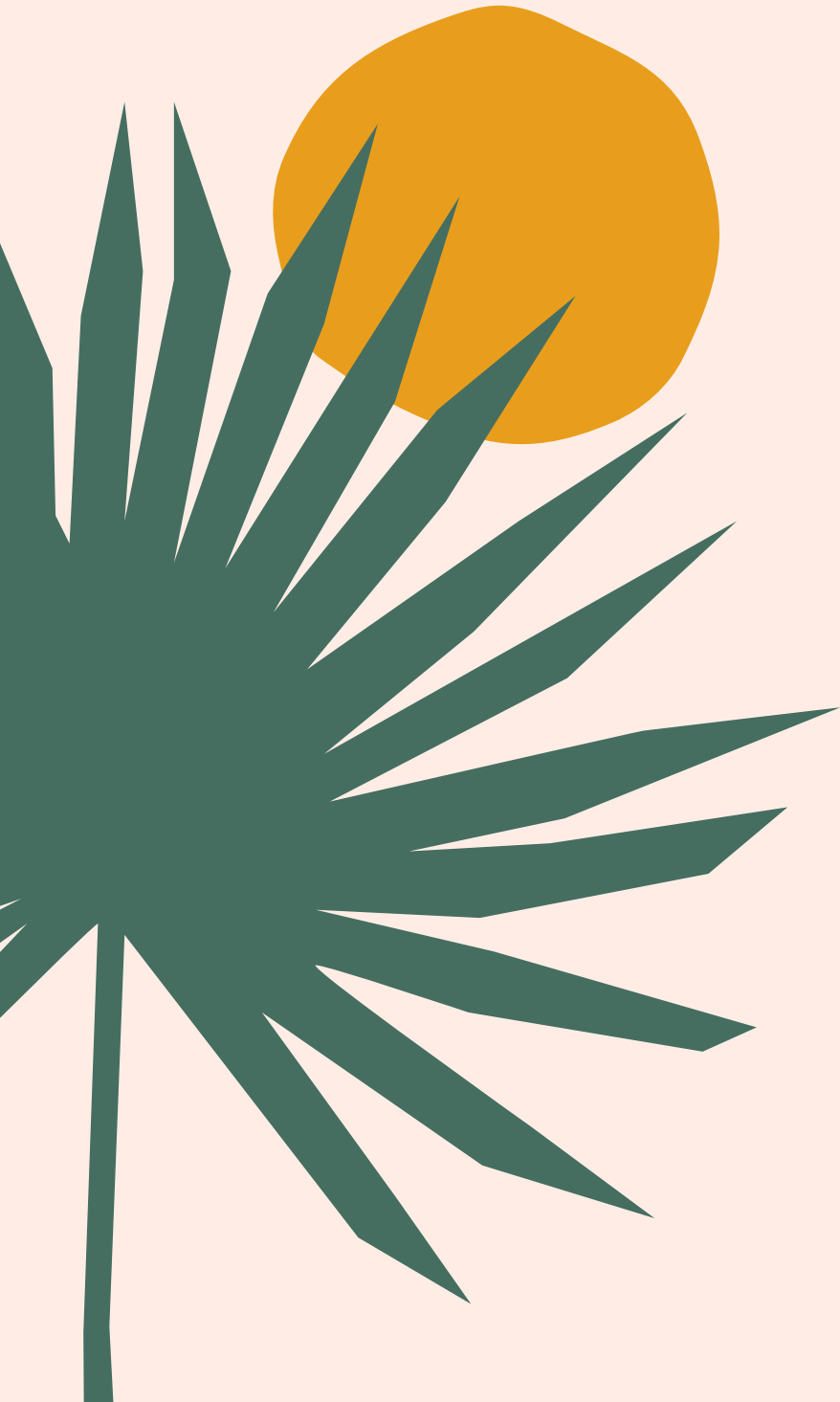
Conclusion

Conclusion

Pacific Islander Data Modernization represents what is possible when research centers and honors community wisdom, and the relationship building required to engage Pacific Islanders. While community representation is the bare minimum in decolonizing research, it also represents the impact of Pacific Islander leadership. Dominant culture methods, such as the Oregon Health Authority Public Health Division's data collection on BRFSS, rendered only 106 responses over three years. Through the leadership of the Pacific Islander community, PIDM engaged: 136 Pacific Islander survey respondents, two Pacific Islander researchers, five Pacific Islander-led organizations that represent countless Pacific Islander community members, and ten Pacific Islander community research workers in a span of six weeks. More importantly, it built a platform for Pacific Islanders to share what our vision of health and healing looks like for our community.

The work cannot stop here. Improving the quality of life for Pacific Islanders in Oregon requires a continuation of robust investments in Pacific Islander Data Modernization. The Core Research Team recommends the following next steps:

1   Map the PI HEAL Assessment community health factors to the State Health Improvement Plan to leverage existing resources and begin immediately addressing the health needs raised in this work.

2   Have the Oregon Health Authority's Public Health Division and Pacific Islander leaders enter into 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.

3   And lastly, continue to celebrate, uplift and invest in the vast brilliance of the people of Oceania.

Appendix

PI Heal Assessment

OVERVIEW

Pacific Islander Data Modernization (PIDM) is a collaborative project between Pacific Islander leaders and the Oregon Public Health Division. PIDM is piloting the Healthy, Equity, and Liberation (HEAL) Assessment in an effort to identify what practices, opportunities, and challenges exist for Pacific Islanders when it comes to health and healing.

INSTRUCTIONS

We know that a core value of Pacific Islanders is caring for the larger community, rather than one individual alone. Rate each of the community health factors by selecting the fish that best represents how accessible and abundant this factor is to Pacific Islanders in Oregon. For example:

How abundant is this community health factor for Pacific Islanders in your area?

Pacific Islander Community Health Factors	Rating
People	
1. **Community Connections**: Trusting relationships among community members built upon shared values, similar histories, and mutual support.	
2. **Care for Community**: Meaningful engagement with social organizations, local politics, churches, etc. to provide resources and advocate for your community.	
3. **Community Values**: There is respect for the land and its Indigenous people, a love for family, and shared responsibility to take care of the community. Elders are also respected, youth have the opportunity to grow as leaders, and LGBTQIA+ people are included.	
Comments about "People" category:	

Bonefish: Myself, my family, and my community do not have this
One little fish: This is something I have personally, but is not something that my family or community have
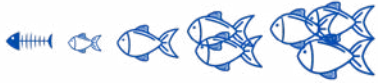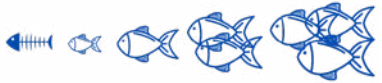**One large fish:** This is something I have and my family have, but not my community
Two fish: This is something I have, my family have, and some of my community have
Three fish: This is something I have, my family have, and my community have

You can skip any question at any time. If you choose to skip a question, you will have a chance to tell us why you did not respond. Your comments will help us improve this assessment.
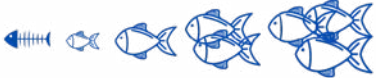
PI Heal Assessment CONTINUED

Place	
4. **Housing**: Safe, affordable, and quality housing that can accommodate families of all forms and sizes (e.g., chosen family, multi-family and/or multi-generational).	
5. **Food**: Sustainable, nourishing, and affordable food is available. Including traditional Pacific Islander ingredients like taro or fresh fish.	
6. **Access to land**: There is access to clean water and land for fishing, growing food, recreation, celebration, or practicing ceremony.	
7. **Getting around**[1]: Sidewalks, public transit, and physical spaces that enable people to access key resources and fully participate in their communities.	
8. **Cultural Centers**: A physical space specifically for Pacific Islanders to gather the larger community to practice culture, have celebrations, provide culturally relevant resources, engage youth, etc.	
Comments about "Place" category:	

PI Heal Assessment CONTINUED

Opportunity	
9. **Living Wages**: Paychecks are enough to pay bills, buy food, save money, and do fun activities with loved ones.	
10. **Local Wealth**: People in the community own their homes; own businesses; and have opportunities to invest in the local economy.	
11. **Education**: There are opportunities for learning in a variety of settings (e.g., homes, schools, communities) that supports the development and growth of students, teachers, and the broader community.	
12. **Information**: Reliable information written and spoken in all Pacific Islander languages so people can access resources and opportunities. The information is accessible to non-English speakers, people who are hearing or visually impaired, and people of all education levels.	

PI Heal Assessment CONTINUED

Healing	
13. **Self Determination:** Pacific Islander expertise is prioritized in all decisions affecting Pacific Islanders. This expertise is valued no matter what your language, income, immigration status, level of education, ability, etc. so that all individuals hold power over what happens in their lives.	
14. **Decolonization**: An end to loss of land, forced migration, militarization of the Pacific, harmful tourism, cultural appropriation and other forms of oppression so that Indigenous peoples and their land can thrive.	
15. **Spiritual Health[2]**: Access to religion, spiritual practices, ceremony, or any resources that provide purposeful guidance in understanding the balance between the different aspects of life.	
16. **Healthcare**: Medical, dental, and vision insurance that covers holistic care for physical and mental health. It is delivered by people who are familiar with and respectful of Pacific Islander culture. The services are easy to get to, easy and quick to schedule, accepting of different insurance plans, and are affordable.	
Comments about "healing" category:	
Anything that you would like to add?	

Glossary of Acronyms & Key Terms

ACEs: Adverse Childhood Experiences. Adverse childhood experiences or ACEs refer to traumatic experiences during childhood that previous research suggests lead to prolonged toxic stress and subsequent poor health outcomes in later life.

BRFSS: The Behavioral Risk Factor Surveillance System. The BRFSS is the largest, continuously conducted telephone health survey in the world and is a collaborative project between the Centers for Disease Control and Prevention (CDC) and US states and territories. The BRFSS survey aims to collect state-specific data on preventive health practices and risk behaviors that are linked to chronic diseases, injuries, and preventable infectious diseases in the adult population.

CDC: The Centers for Disease Control and Prevention.

COFA: Compact of Federal Association. The Compact of Free Association is an agreement between the US and several Pacific Island nations. The COFA agreement was established in response to a lawsuit for damages associated with nuclear weapons testing conducted in island waters by the US after World War II. The lawsuit resulted in a treaty, now known as the COFA agreement, between the US and the Republic of the Marshall Islands, the Federated States of Micronesia, and the Republic of Palau. The agreement affords COFA citizens the right to travel, work, and live in the US without a visa in exchange for the US maintaining a military presence on these islands. COFA citizens are obligated to pay US federal, state, and local taxes, but are not eligible to vote or access certain benefits. Access to federal Medicaid was recently restored for COFA citizens after a 1996 welfare reform bill excluded them from the program for more than two decades.

CBOs: Community-based organizations.

CRWs: Community Research Workers.

DSA: Data Sovereignty Agreement.

ESL: English as a Second Language. Also sometimes referred to as English Language Learners (ELL).

LGBTQIA+: Lesbian, Gay, Bisexual, Trans, Queer/Questioning, Intersex, Asexuality. The "+" symbol recognizes all of the other sexual identities, genders, and sexes that are not included in these letters.

OHA: Oregon Health Authority.

OPHD: Oregon Public Health Division.

Glossary of Acronyms & Key Terms

PDES: Program Design and Evaluation Services, an applied research and evaluation unit that is shared between Multnomah County Health Department and the Oregon Health Authority's Public Health Division.

PI: Pacific Islander.

PIDM: Pacific Islander Data Modernization.

PIDP: Pacific Islander Data Project.

PI HEAL: Pacific Islander Health, Equity, and Liberation assessment.

MCHD: Multnomah County Health Department in Multnomah County, Oregon.

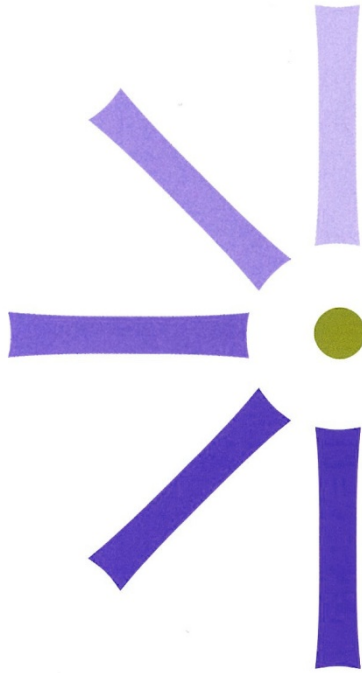**REALD:** Race, ethnicity, language, and disability.

SOGI: Sexual orientation and gender identity.

THRIVE: Tool for Health and Resilience in Vulnerable Environments, a community health assessment from the Prevention Institute and part of the inspiration for the PI HEAL assessment.

US: United States.

THIS IS THE WAY WE RISE

PARTICIPATORY ANALYSIS

Expanding Stakeholder Involvement in Evaluation

Veena Pankaj
Myia Welsh
Laura Ostenso

April 2011

innovation network
TRANSFORMING EVALUATION FOR SOCIAL CHANGE
www.innonet.org

Participatory Analysis:

Expanding Stakeholder Involvement in Evaluation

Veena Pankaj, Myia Welsh, and Laura Ostenso

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

Over the past year, Innovation Network has begun to use **participatory data analysis** as part of our overall **participatory evaluation** approach (see sidebar). This paper offers brief case studies examining the use of participatory analysis with three different organizations: The Congressional Hunger Center, Washington Area Women's Foundation, and ACTION (Advocacy to Control Tuberculosis Internationally). Each case study includes a description of the purpose of the participatory analysis; the design, planning, and implementation process; and the effect on the overall evaluation. The paper concludes with tips for getting started with participatory analysis.

Why We Began Using Participatory Analysis

Innovation Network has been a longtime proponent of participatory evaluation. The vast majority of our evaluation consulting engagements since 1992 have used a participatory approach. However, we recently realized that much of the "participatory-ness" of our evaluation projects was limited to the evaluation planning stage. Sometimes stakeholders would continue to be involved in implementing the evaluation—offering input on data collection instruments, for example, or being active participants in data collection. However, we felt that other opportunities for participation were being overlooked.

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Participatory Evaluation

Participatory evaluation is not new: It has philosophical and social roots going back at least to the 1960s, and began to gather momentum as an evaluation approach in the late 1980s.* Participatory evaluation involves engaging a program's stakeholders in the evaluation process—making them active participants, rather than passive subjects.

In the early years of Innovation Network's evaluation practice, we found that many nonprofits viewed evaluation as a punitive process that is "done to" them. We adopted participatory approaches to help change that perception—to draw on the wisdom of the people implementing the programs, and to make evaluation an opportunity for learning.

Benefits of participatory approaches include:

- Informing the evaluation planning process with multiple insider perspectives;
- Ensuring mutual understanding between the evaluation team and the program stakeholders of the program's intended goals, strategies, and desired outcomes—and the purpose of the evaluation process.
- Making evaluation results more useful for communications, fundraising, and program improvement.

* For an overview of participatory evaluation's origins, see "The History of Participatory Evaluation and Current Debates in the Field," by Sharon Brisolara, published in the Winter 1998 edition of *New Directions for Evaluation*.

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How We Use Participatory Analysis

To fill this participation gap, we began involving stakeholders in the **analysis and interpretation** of the data, rather than simply offering a final evaluation report with findings and recommendations drawn from our analysis. Participatory data analysis can be used to:

- Present first drafts of data and/or findings, giving stakeholders the chance to provide context and input on findings or recommendations;
- Help sustain stakeholder interest and engagement in the evaluation process;
- Identify which findings and recommendations are the most meaningful to stakeholders; and
- Increase the likelihood that findings and recommendations will be put to practical use.

Participatory analysis can take many forms, but generally is prepared for and facilitated by the evaluator. The evaluator develops the agenda and prepares presentation materials that will elicit constructive discussion. The following case studies illustrate three different approaches we have used.

Case Study:

Congressional Hunger Center—Data Placemats for Improved Reporting

The Congressional Hunger Center is a Washington, D.C.-based nonprofit organization. Its mission is to train and inspire leaders who work to end hunger and to advocate for public policies that create a food-secure world. Innovation Network partnered with the Congressional Hunger Center to evaluate its Bill Emerson National Hunger Fellows Program. The evaluation sought to assess:

- Impact on the educational and career objectives of participants;
- Participants' understanding of the connections between hunger, poverty, and racism;
- Effect of professional connections made during the fellowship;
- Benefits to the operations of placement organizations and communities (where fellows worked);
- Overall quality and utility of the training portion of the program;
- Quality of the support provided to fellows by Emerson Hunger Fellows staff.

We collected evaluation data through a survey of past Emerson Hunger Fellows, and by interviewing key informants such as program staff, program alumni, site supervisors from the placement organizations, and members of the Congressional Hunger Center's Board of Directors. To prepare for the participatory analysis meeting, we synthesized and organized the data into topic areas emerging from preliminary analysis and related to the evaluation's goals. We chose to present the preliminary data as a series of "data placemats"—large sheets of paper displaying thematically grouped data. Each placemat presented data through charts, graphs, and quotes, displayed in a visually pleasing, easy-to-follow format. While the purpose of the placemat is to allow stakeholders to independently ponder and analyze the data, it is up to the evaluator to decide which data will be included, and how to effectively organize and display them.

Figure 1: Anatomy of a Data Placemat
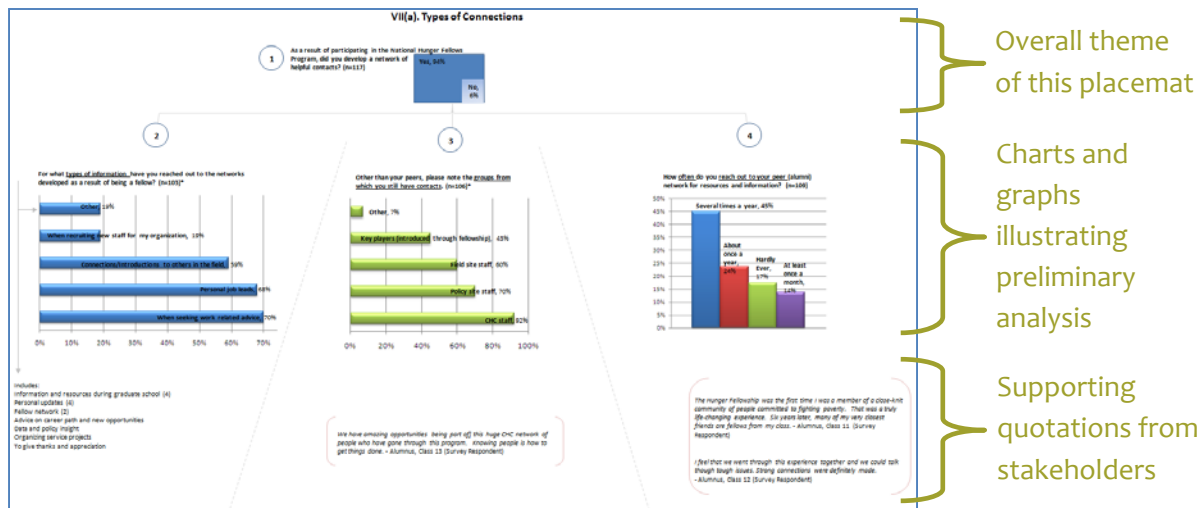
The three-hour participatory analysis meeting was attended by the evaluators and the two co-directors of the Emerson Hunger Fellows program. The objective of the meeting was to elicit stakeholder feedback by presenting the preliminary data using the eleven placemats. The evaluators guided stakeholder discussion using three questions:

- What surprises you about the data?
- What factors may explain some of the trends we are seeing?
- Does this lead you to new questions?

As a result of the participatory analysis meeting, the quality of evaluation findings and recommendations was strengthened, stakeholder buy-in for findings/recommendations was increased, and the likelihood of evaluation use improved. By involving stakeholders in analysis, the evaluators better understood the context and therefore the meaning of the data, resulting in added nuance and richness of the final evaluation report. We were pleased to hear that Congressional Hunger Center staff has used the report as an advocacy tool on Capitol Hill.

Lessons Learned

Improved Reporting: The participatory analysis approach using data placemats led to a more comprehensive, detailed report that told a more accurate story of program implementation and impact—more so than if stakeholders had not engaged in the participatory analysis. The approach also simplified the development of the final report: Evaluators and stakeholders had discussed and agreed to findings, preliminary data visualizations had already been created for the placemats, and fewer drafts were exchanged between evaluators and stakeholders.

Visual Presentation of Data: When designing data communication tools, such as the data placemats, it is important that the evaluator communicates information in a clear, user-friendly way that best portrays the data. The evaluator should provide an unbiased analysis of key data, organized by evaluation question, outcome, or other topic. When appropriate, charts, graphs, and other visualizations should be used to increase the ability of stakeholders to understand relationships among the data. Careful attention to visual design helps stakeholders to easily understand the data, paving the way for rich conversation.

Effect on Project Scope: Though participatory analysis simplifies some aspects of the evaluation process, it is not without cost. Preparation for participatory analysis takes time, and necessitates the creation of an additional product—the data placemats (or other presentation materials). The time that it takes to engage in participatory analysis—performing the preliminary data analysis, creating the visualization-intensive placemats, and conducting the analysis with stakeholders—should be included in the evaluation project workload estimate.

Case Study:

Washington Area Women's Foundation—Setting Realistic Expectations and Increasing Support with Stakeholders

Washington Area Women's Foundation is a regional foundation that seeks to improve the lives of women and girls in the D.C. area through leveraging women's philanthropy and providing grants to local organizations. Innovation Network partnered with the Washington Area Women's Foundation on a five-year evaluation of the Stepping Stones Initiative, a multi-year effort designed to build the long-term economic security and financial independence of female-headed households in the D.C. metropolitan area. The evaluation tracked progress made on initiative outcomes across multiple grantee projects.

In the first four years of the project, a traditional evaluation report was submitted with minimal analysis discussion. After staffing changes on both the evaluation side and at the Foundation, we opted for a new approach to keep the evaluation stakeholders engaged with the evaluation process.

In the fifth year of the Stepping Stones project, a participatory analysis meeting was held in preparation for creating the year-end report. The evaluation team collected data from grantee reports, media scans, and program participant interviews. The team then compiled and analyzed data in preliminary thematic categories, with the purpose of presenting the data in a comprehensible but unbiased fashion. The format of the participatory analysis meeting was a visual slideshow of the data, formatted into charts and graphs, accompanied by facilitated discussion.

This format provided the space for open sharing of feedback, and resulted in:

- Increased clarity about the influence of economic and political factors on the data;
- Improved stakeholder understanding of the data and its limitations, and what findings could realistically be drawn from the data;
- Buy-in and support for findings and recommendations;
- Simplified production of the final report;
- Improved evaluator-stakeholder communications and relationship; and
- Improved stakeholder confidence in using the data for reporting and fundraising.

Lessons Learned

Reasonable Expectations: The participatory analysis meeting increased stakeholder understanding about which conclusions could realistically be drawn from the data, setting reasonable expectations that led to more support for the findings and recommendations contained in the final report. Including stakeholders in the analysis phase reinforced to them that their perspective was vital to understanding the data, and that the evaluator does not have the last word.

Stakeholder Support: The process also revitalized stakeholder support for the evaluation, which was crucial as the project was in its fifth year and had experienced significant staff turnover. In year five, not a single person remained who had been involved in the initial design and implementation of the evaluation project in year one. The participatory analysis process fostered engagement and understanding that may not have been present otherwise.

Case Study:

ACTION—The Importance of Who is at the Table

ACTION (Advocacy to Control Tuberculosis Internationally) is a global partnership working to bring additional funding resources and attention to the fight against tuberculosis. ACTION uses what it calls an "inside/outside" advocacy approach—its strategies are targeted "inside" (i.e., within governments and institutions) and "outside" (i.e., in the field) to achieve maximum effect.[1]

ACTION uses an internal evaluation system to track outputs, such as the amount of media generated, number of citizen advocates mobilized, and amount of outreach to decision makers. It also partners with external evaluators to conduct third-party evaluations. In 2010 for a grant midterm evaluation, ACTION partnered with Innovation Network on an evaluation for the dual purpose of accountability and learning.

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[1]For more on ACTION's internal/external advocacy, visit http://www.action.org/site/publications/best_practices

The evaluation addressed five evaluation questions:
- What progress has been made toward national-level advocacy goals?
- What progress has been made toward multilateral advocacy goals?
- What advocacy capacity has been built? Is it sustainable?
- What is unique and valuable about ACTION's model?
- Where/how else can ACTION play a role/add value?

The evaluation team collected data through a variety of methods, including:
- A survey of ACTION partner staff in all country offices: the U.S., U.K., Kenya, Japan, France, Australia, Canada, and India;
- Key informant interviews with 35 internal and external stakeholders including program staff, outside partners, and technical experts;
- Focus groups with the Secretariat staff, country campaign staff, and an intense period debrief[2] with Secretariat staff after ACTION's annual meeting and conference campaign period; and
- Document review.

In contrast to the two preceding case studies—for which the majority of data was quantitative and thus easily represented using charts and graphs—the ACTION evaluation project collected mostly open-ended survey and interview data. Since charts and graphs were less useful in this case, the evaluators decided to draft preliminary findings organized by the evaluation questions listed above. Each preliminary finding was supported by verbatim quotes taken from survey data and interview/focus group transcripts. In contrast to the preceding two case studies (in which findings were co-developed with stakeholders based on the data), the purpose of the participatory analysis meeting with ACTION staff was to solicit stakeholder feedback on preliminary findings and gather input into recommendations.

Careful attention was given to selecting the right stakeholders to attend the meeting. While a broad pool of stakeholders was involved in contributing to the design of the evaluation (e.g., developing evaluation questions and identifying interviewees), it was acknowledged that a smaller group was needed to provide strategic review. Seven ACTION project staff members, representing a breadth and depth of organizational knowledge and skills, were selected to engage in the participatory analysis process. The participant list was finalized through conversations between the evaluators and the primary contact of the ACTION project.

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[2] The Intense Period Debrief is a data collection methodology developed by Innovation Network specifically for advocacy evaluation. Learn more at http://www.innonet.org/client_docs/File/advocacy/intense_period_debrief.pdf

In the first meeting (90 minutes in length), the evaluators presented each finding accompanied by the supporting quotes. A slideshow presentation was used to display the findings, participants were each given a hard copy of the full findings, and table cards reminded participants of the guiding questions for the meeting. The three questions used to guide discussion were:

- How does this information align with your experience and perceptions?
- What doesn't fit? How?
- Where would you add context to clarify or explain the findings?

In the second meeting (60 minutes in length), the conversation focused on recommendations. The evaluators presented recommendations gleaned from the data, and participants were asked to reflect on which recommendations were most relevant to ACTION's continuing work considering its priorities and resources. The evaluators believed that the final recommendations developed through the participatory process were more relevant, useful, and actionable than otherwise would have been generated.

ACTION staff input resulted in the creation of recommendations relevant to nascent strategies and priorities—developments so new that they were not included within the scope of the evaluation and would have otherwise been overlooked by the evaluators. For example, one finding spoke to the power of an ACTION representative occupying a Board of Directors seat at the Global Fund to Fight AIDS, Tuberculosis, and Malaria (one of the multilateral bodies targeted by ACTION advocacy). What the evaluation did not capture was that the Director term was nearly complete, and the ACTION representative would rotate off of the Board in a matter of months. When presented with the finding regarding the power of the Director position, ACTION staff were not surprised—they had already begun to think about the issue. In the participatory analysis meeting, staff applied their deeper contextual knowledge to the finding, noted that the term was nearly complete, and voiced a recommendation that a similar position should be sought with another organization targeted by ACTION advocacy.

Lessons Learned

Choose the Right Participants: Part of the art of the participatory analysis approach is deciding *who is at the table*. ACTION is a big partnership with nearly 60 staff internationally, from nine formal international partners. They are a busy, dynamic group spread across multiple time zones. For the meeting to be successful, participants needed to be able to have a conversation of depth (as opposed to breadth), and needed to be in action/decision making positions capable of speaking for the organization. Having a representative mix of stakeholders who could make high-level, partnership-wide recommendations was extremely valuable.

Budget Appropriate Resources: Participatory analysis is time consuming: time to conduct the preliminary analysis, to prepare the data communication tools, to plan for the presentation, and to conduct the meeting. These meetings can also be quite intense, requiring skilled facilitation. Depending on how much information there is to present, it may be preferable to split the session across two days— for example, a day to review findings, and a second day to firm up recommendations.

Participatory Analysis: Getting Started

Participatory analysis is a valuable tool in the evaluator's toolbox, but like a hammer, it isn't the right tool in every situation. In determining whether participatory analysis may be a good fit for your evaluation needs, consider the following questions:

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

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