

# Engaging Communities in the Modernization of a Public Health Survey System

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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	
<b>Expensive</b>	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.
<b>Survey burden</b>	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.
<b>Representativeness</b>	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.
<b>Validity</b>	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.
<b>Lack of community engagement</b>	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.
<b>Lack of data on the Pacific Islander community</b>	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)<sup>1</sup> 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.



<sup>1</sup> 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)<sup>2</sup>, 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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<sup>2</sup> 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 8 <sup>th</sup> & 11 <sup>th</sup> 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 8 <sup>th</sup> & 11 <sup>th</sup> 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
<ol style="list-style-type: none"> <li>1. Do you have <b>any kind of health care coverage</b>, including health insurance, prepaid plans such as HMOs, government plans such as Medicare or Indian Health Services?</li> <li>2. Are you <b>currently enrolled in the Oregon Health Plan (OHP)</b>, which is the State's Medicaid program?</li> <li>3. Do you have one person who you think of as your <b>personal doctor or health care provider</b>?</li> <li>4. Was there a time in the past 12 months when you needed to see a doctor but could not because of the <b>cost</b>?</li> <li>5. About <b>how long has it been</b> since you last visited a doctor for a routine checkup?</li> </ol>	<p>Do any of the following <b>prevent</b> 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.</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> CCO/health <b>provider is too far away</b></li> <li><input type="checkbox"/> Don't have access to <b>transportation</b></li> <li><input type="checkbox"/> Don't have access to <b>childcare</b></li> <li><input type="checkbox"/> Don't have consistent access to <b>internet</b> for virtual appointments</li> <li><input type="checkbox"/> Don't have <b>health insurance</b></li> <li><input type="checkbox"/> <b>Process for making an appointment</b> with a provider is difficult</li> <li><input type="checkbox"/> <b>Don't feel safe</b> visiting my provider</li> <li><input type="checkbox"/> <b>Provider cannot communicate in a language</b> that I'm comfortable using</li> <li><input type="checkbox"/> Provider doesn't have the same <b>cultural background</b> as me</li> <li><input type="checkbox"/> The <b>service(s) I/we need is not covered</b> by my insurance</li> <li><input type="checkbox"/> The <b>service(s) I/we need is not available</b> near me</li> <li><input type="checkbox"/> <b>Not aware of what services are available</b> near me</li> <li><input type="checkbox"/> Information about services is not provided in a <b>language</b> that I'm comfortable using</li> <li><input type="checkbox"/> <b>Don't trust that my CCO/health provider will be respectful of my cultural values</b></li> </ul>

### 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

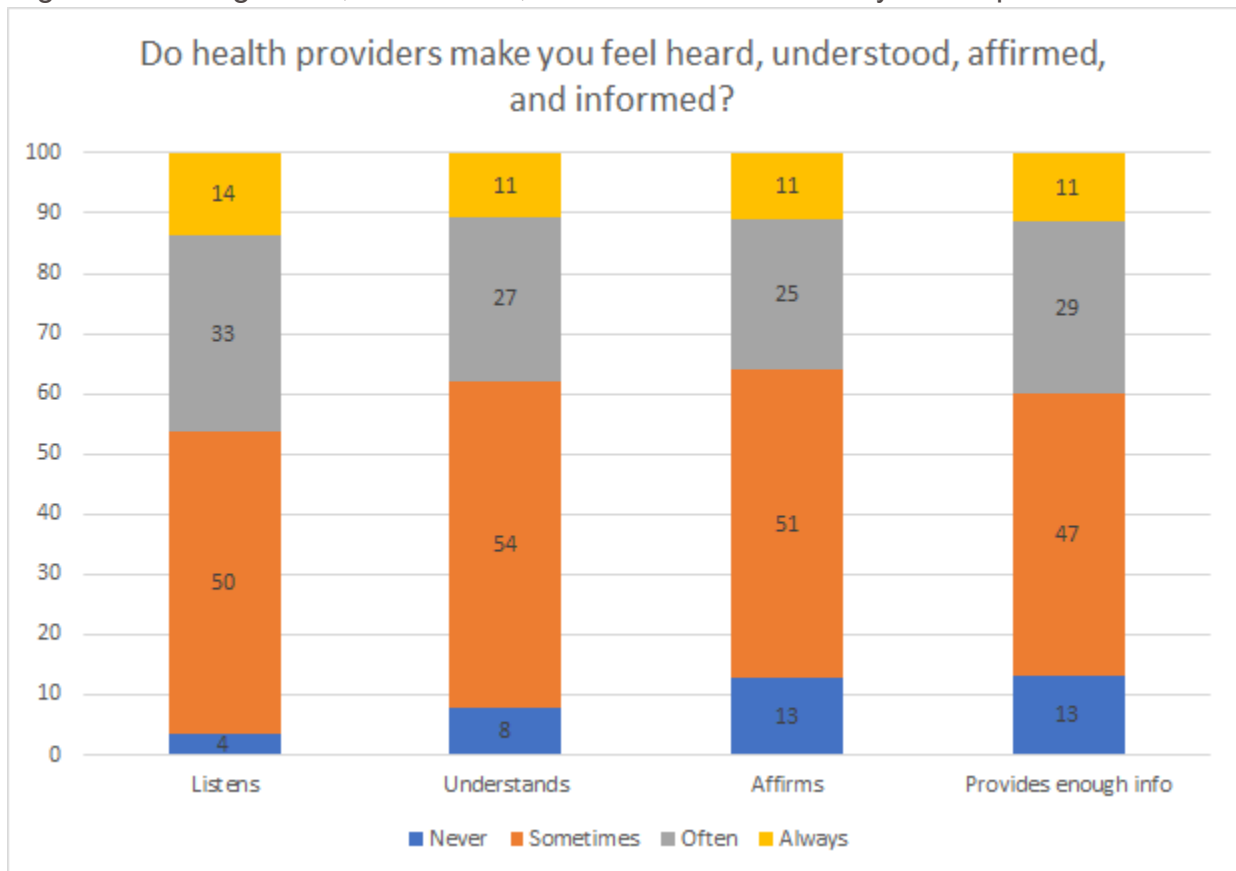


Figure 1. demonstrates that 53-64% of respondents never or only sometimes feel heard, understood, affirmed and informed when seeing a health provider. These data point to bucket areas that require further investigation. What is it about one's visit with a health provider that folks do not feel heard, 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	<ul style="list-style-type: none"> <li>● Dismissive</li> <li>● Patient feels unheard</li> <li>● Disrespectful</li> <li>● Rushed appointments</li> </ul>
Experiences of harmful care practices	<ul style="list-style-type: none"> <li>● Denied care</li> <li>● Misdiagnosis</li> <li>● Unnecessary treatment</li> <li>● Need to self-advocate</li> </ul>
Stereotyping by providers	<ul style="list-style-type: none"> <li>● Presumed incompetent</li> <li>● Assumed drug addiction</li> </ul>

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	<ul style="list-style-type: none"> <li>● What activities do you do outside of school?</li> <li>● Do you feel like you have the information to know how to fix your issues?</li> <li>● What are some factors in your life that may disrupt your ability to do best in school?</li> <li>● Do you ever talk to people about what kind of support you need to achieve your goals?</li> <li>● Do you live in a safe environment?</li> </ul>
More specific questions about mental health	<ul style="list-style-type: none"> <li>● How do you cope with all the different expectations on your plate?</li> </ul>

Themes	Examples
What is going well currently and future goals	<ul style="list-style-type: none"> <li>● How do you think you can stay strong throughout the year?</li> <li>● Are you feeling stressed out about something? If so, who can help you feel better?</li> </ul>
What is going well currently and future goals	<ul style="list-style-type: none"> <li>● What is currently going good for you?</li> <li>● Do you have goals or plans for your future?</li> </ul>

## 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?
<p>During the past 12 months, how many days of school did you miss –</p> <ul style="list-style-type: none"> <li>● for any reasons?</li> <li>● because of physical health reasons?</li> <li>● because of emotional or mental health reasons?</li> </ul> <p>How many days of school did you have unexcused absences (meaning you skipped or cut school)?</p> <p>Did you miss one or more hours of school due to any of the following reasons?</p> <ul style="list-style-type: none"> <li>● I had a toothache or painful tooth;</li> <li>● My mouth was hurting;</li> <li>● I had to go to the dentist because of tooth or mouth pain;</li> <li>● I had to go to the hospital emergency room because of tooth or mouth pain;</li> <li>● I had a mouth injury from playing sports</li> </ul>	<ul style="list-style-type: none"> <li>● Just ask them “What’s causing you to miss school?” (open ended)</li> <li>● Do you have problems at home/outside of school?</li> <li>● Are you doing ok?</li> <li>● After each question just add a “why section”</li> <li>● What is elevated above school? Why does it come up?</li> <li>● Do you have other things to do other than school?</li> <li>● What are things affecting you outside of school that keep you from being successful?</li> <li>● In what ways does school feel unsafe to you?</li> <li>● Is someone making fun of you or are there stressful conditions you want to avoid at school like students or teachers?</li> <li>● What would make school a safer environment?</li> <li>● What at schools feels welcoming/accepting? What does not?</li> </ul>

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?
<p>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?</p>	<p>Understanding of what’s preventing them from being physically active</p> <p>Mapped in relation to policy-related physical activity contexts. Examples:</p> <ul style="list-style-type: none"> <li>● Joint use agreements between schools and public</li> <li>● Amount of greenspace</li> <li>● % of jurisdiction zoned for public recreation use</li> <li>● Density of free gym facilities as ratio of non-free ones</li> <li>● Traffic/pedestrian injury rates</li> <li>● Sidewalk existence &amp; quality</li> <li>● % of tax revenue invested in parks</li> </ul> <p>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?</p>

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?”

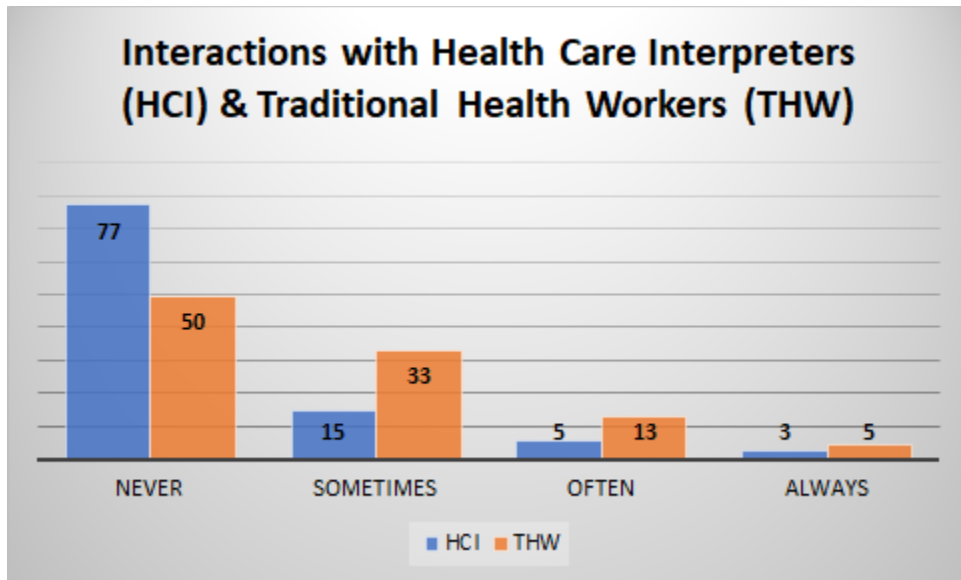
### Use of health care interpreters & Traditional Health Workers

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)<sup>3</sup> 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.

<sup>3</sup> 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

<p>How easily can you access support for issues around stress, frustration, worry, anger, addiction, violence, and/or abuse from providers who understand your <b>cultural background</b>?</p>	<p>¿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 <b>origen cultural</b>?</p>
<p>How easily can you access support for issues around stress, frustration, worry, anger, addiction, violence, and/or abuse from providers who <b>speak your language</b>?</p>	<p>¿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 <b>hablan su idioma</b>?</p>

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

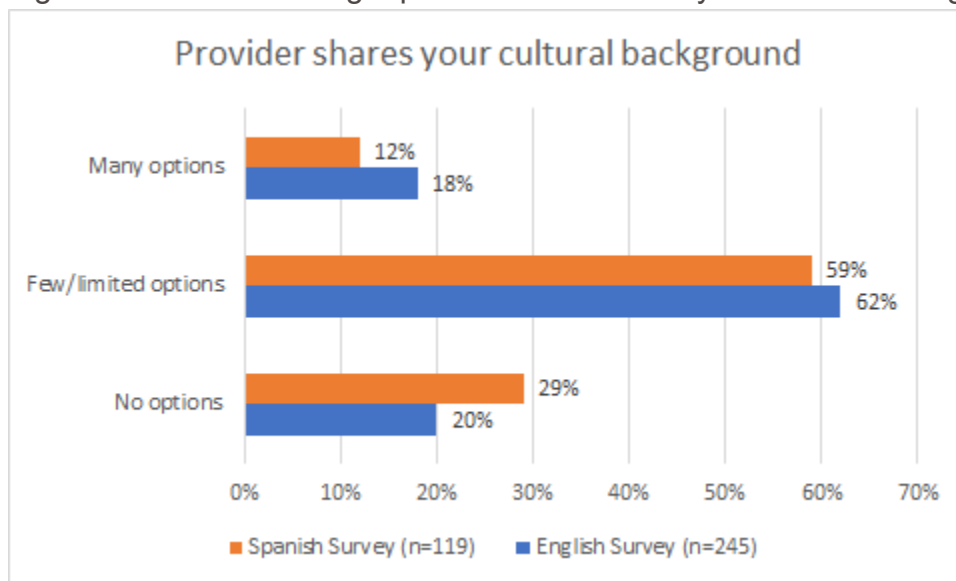
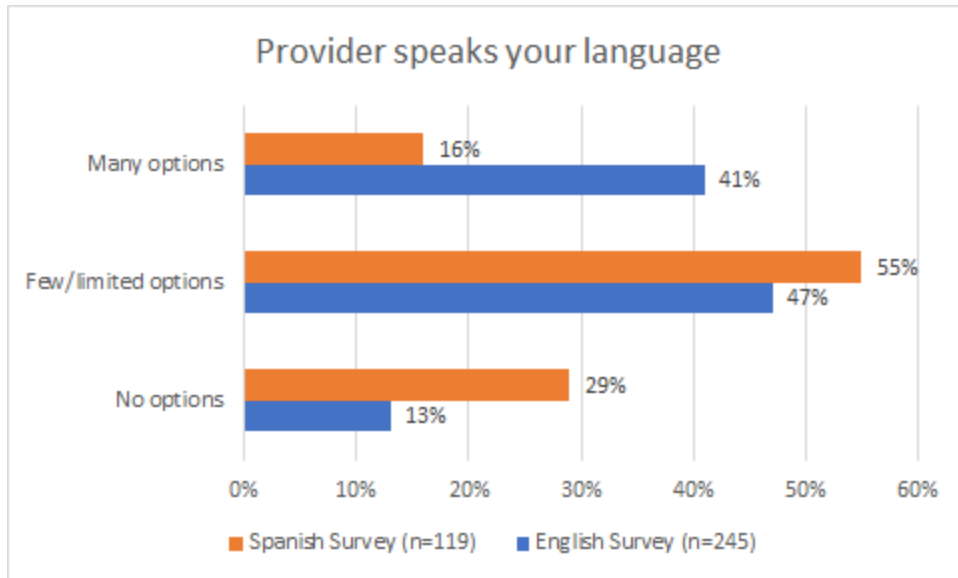


Figure 5. Ease of finding a provider who speaks your language



## 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.

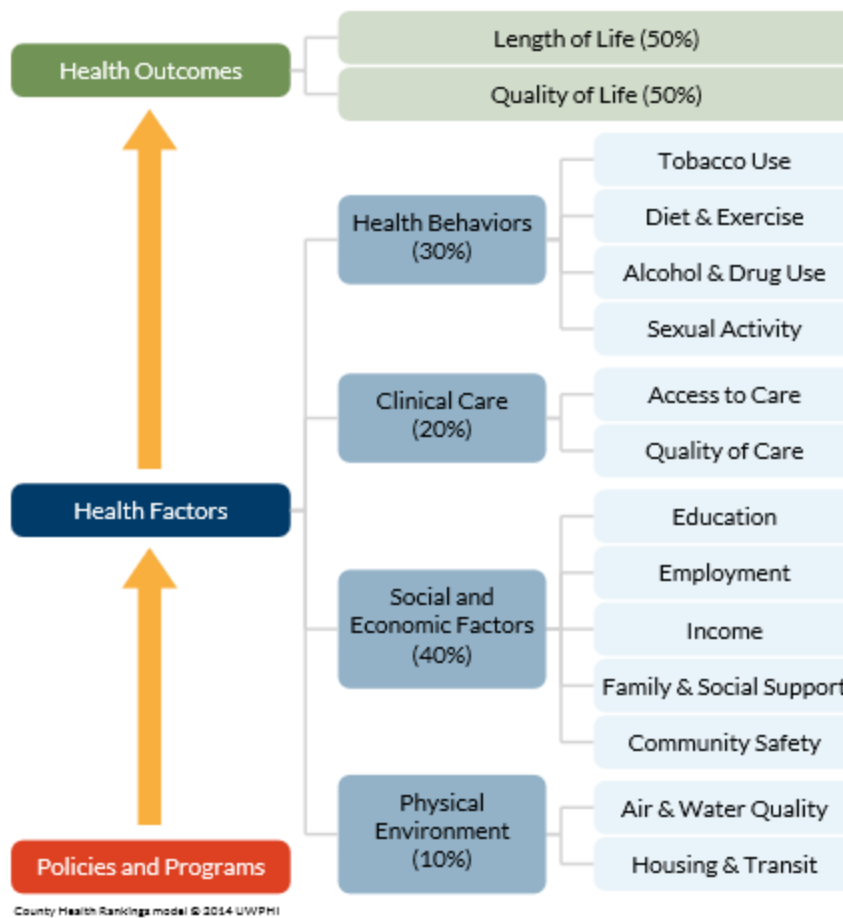
- Build in **time and resources necessary for relationship development** between governmental public health and community partners in data
- Continue **long term, sustained compensated Community led Data Collection**
- Facilitate the use and application of community led data collection by OHA
- Conduct 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).

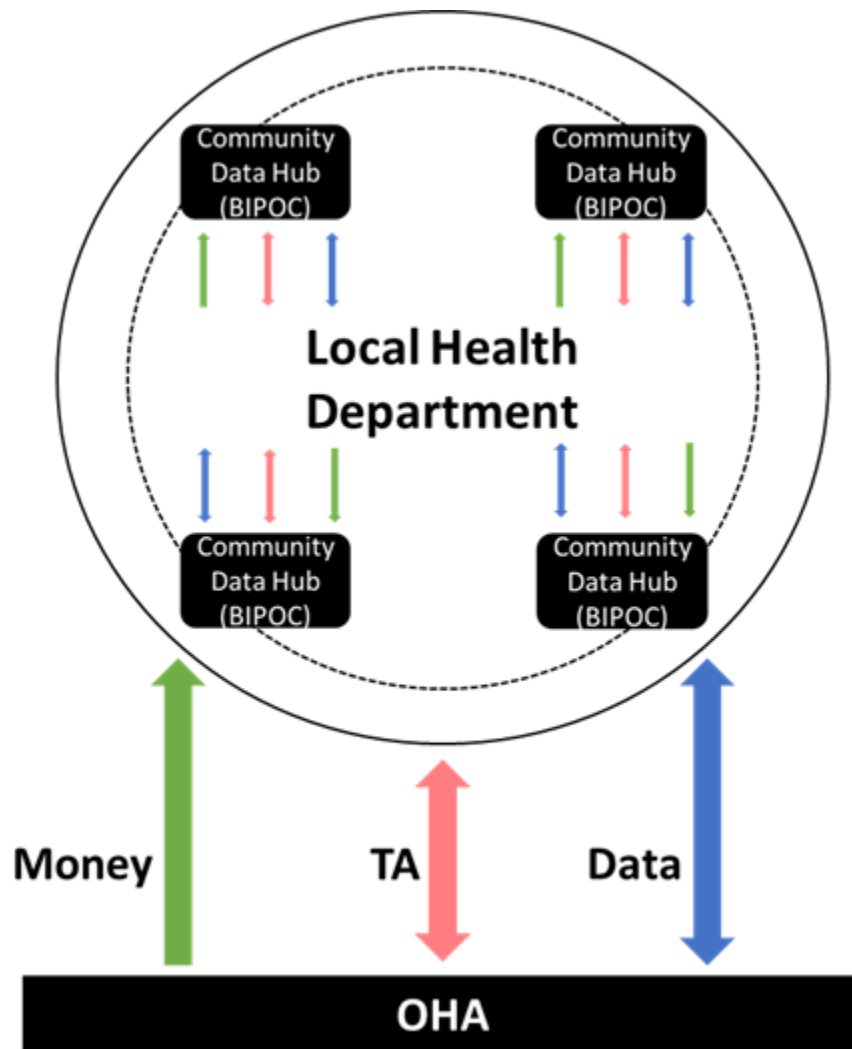
The County Health Rankings was one conceptual framework provided.

Figure 6. County Health Rankings Model



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.<sup>4 5 6 7 8</sup>

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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<sup>4</sup> CDC Racism as Threat to Public Health <https://www.cdc.gov/healthequity/racism-disparities/index.html>

<sup>5</sup> AMA Racism as Threat to Public Health <https://www.ama-assn.org/delivering-care/health-equity/ama-racism-threat-public-health>

<sup>6</sup> APHA Racism and Health <https://www.apha.org/topics-and-issues/health-equity/racism-and-health>

<sup>7</sup> 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

<sup>8</sup> 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*

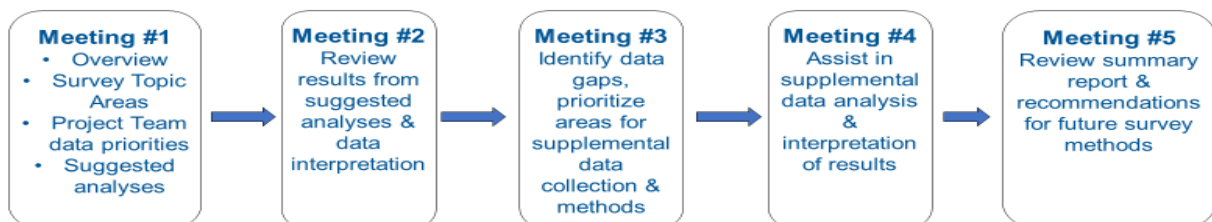
Extensive partnership infrastructure building took place between October 2019- March 2020 to develop community specific data project teams of 4-5 individuals consisting of both researchers who are community members and have conducted community specific health related research and representatives from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



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

### COMMUNITY-LED DATA COLLECTION METHODS

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.

#### Youth Health

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 11<sup>th</sup> 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\*

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

<b>Black/African American (n=123)</b> <b>36%</b>	<b>Latinx (n=183)</b> <b>54%</b>
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.