

COMMUNITY BRIEF

SUMMER 2023



INTRODUCING THE WORK

This community brief is about what a community-government collaboration can look like and accomplish when guided by data equity. We describe how this collaboration critically reviewed and reshaped a long-established public health practice: collecting youth data via the Oregon Health Authority's (OHA) Student Health Survey (SHS)*. We summarize our process, findings, and recommendations and illustrate how community-government partnerships can lead to more equitable data practices by centering the needs and desires of communities closest to the issues.

A similar process was undertaken with the Behavioral Risk Factor Surveillance System (BRFSS) and its own community brief can be read [here](#). A visual summary of this process is in Figure 1 on page 07. A more detailed discussion of this work is included the report "Engaging Communities in the Modernization of a Public Health Survey System," which was published in 2021. The report can be accessed [here](#).

In this brief, we use the term "research" to describe certain aspects of this collaboration. We recognize that research in public health means the production of generalizable knowledge. Here, when we mention research, we mean a process of inquiry designed to improve the quality of public health practices (e.g. the SHS).

The primary authors of this brief are Dr. Mira Mohsini (Coalition of Communities of Color) and Dr. Roberta Hunte (Portland State University), who worked as community partners on this project. This brief benefited from the review and feedback of Dr. Kusuma Madamala (OHA), Dr. Ryan Pettaway (Portland State University), Dr. Daniel Lopez

*Prior to 2020, student health data was collected by the Oregon Healthy Teens (OHT) survey. OHT has been renamed to the Student Health Survey (SHS). The OHT was administered in odd-numbered years. Starting in 2020, the SHS is administered in even-numbered years.

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DATA EQUITY

Data equity refers to strategies and practices that promote fairness and limit the harm that dominant data can reproduce. When we say “dominant data” we mean data about people that is collected and used to support and advance the agendas of dominant/powerful institutions (e.g., governments, universities, businesses/for-profits, foundations). These data are typically collected via surveys and presented as numbers and statistics. Data equity should be included in all parts of the data life-course. Below we provide some examples of strategies and practices that advance data equity:

- Community Partnerships
 - Partnering with community members throughout the data life-course: research design, data collection, data analysis, and dissemination of findings
 - Fairly compensating community partners
- Community-Led Question Development & Data Collection
 - Co-constructing survey questions with those closest to the issues being researched
 - Collecting data about the contexts of lived experiences
 - Collecting disaggregated data on race, ethnicity, language, disability, sexual orientation, and gender identity
- Collaborative Data Analysis
 - Interpreting data in collaboration with community members
 - Avoiding interpreting data in ways that reinforce deficit narratives about marginalized groups
- Responsible Communication
 - Being transparent about the limitations of dominant data
 - Providing context about the data (e.g., who collected it, how it was collected, who analyzed it, how it was analyzed)
 - Sharing research findings in culturally and linguistically appropriate ways

Many people think of data as numbers alone, but data can also consist of words or stories, colors or sounds, or any type of information that is systematically collected, organized, and analyzed.

D'IGNAZIO & KLEIN (2020), DATA FEMINISM, P.14



Odd ratios are not going to carry us off to some utopian state of achieved health equity. Health is fundamentally political, and we are inescapably human. Every one of us lives a contested existence, some of us more than others.

RYAN PETTAWAY (2021), "DREAMS OF A BELOVED PUBLIC HEALTH: CONFRONTING WHITE SUPREMACY IN OUR FIELD"



STUDENT HEALTH SURVEY (SHS)

Oregon public health programming relies on data gathered by the Student Health Survey (SHS). Students in grades 6, 8, and 11 can voluntarily complete the SHS survey, which is administered in even-numbered years. Some of the question areas covered in the survey include physical and mental health, food insecurity, sexual health, substance abuse, and school absenteeism. Responses to survey questions generate data that is used to invest in targeted services, secure grant funding, address emergent health issues, inform proposed legislation, and measure progress toward public health objectives.

DATA EQUITY CONSIDERATIONS FOR SHS

The data gathered by the SHS has a lot of power and is used to make decisions that impact the everyday lives of students, their families, and their communities. Over sixty percent of funding for the survey comes from public health programs such as Tobacco Prevention and Control Program, Maternal and Child Health, Adolescent and School-based Health, and Problem Gambling. Most questions on the SHS reflect the interests of these programmatic areas. But these survey questions fail to gather data about the contexts of teens' experiences; in other words, decision makers don't have enough information to take meaningful action.

For example, several questions ask teens about how much school they've missed due to physical, emotional, or mental health reasons. Responses to these questions produce data in the form of a statistic: X percent of 11th graders miss school because of mental health reasons. But we don't know the context in which students are having mental health issues. Is it connected to stress in their family life because they care for their elderly grandparents after school? We don't know because the survey questions focus on individual experiences and behaviors rather than the context that shapes them.



Surveys like SHS need to ask better questions that reflect lived experiences; community members should be part of the process of constructing those questions; and community members should be involved with analyzing and interpreting survey results, which will guide decision makers on how and where to spend resources. These are the strategies and practices needed for data equity, but have been missing from the SHS.

OUR COLLABORATION

In 2019, the Program Design and Evaluation Services (PDES) team within OHA assembled a group of community members to provide guidance on the shortcomings of youth survey data and how OHA can collect better youth data. Two culturally specific workgroups were formed – Black/African American and Latinx – that met regularly to review the results of community-led data collection and provide recommendations to OHA. Researchers from the Research Justice Institute at the Coalition of Communities of Color (CCC) facilitated and worked closely with both workgroups and PDES team members. Two other culturally specific groups – Pacific Islander and American Indian/Alaska Native workgroups – also participated in survey modernization efforts and produced separate recommendations. These reports can be found [here](#).

The workgroups identified many shortcomings in the SHS including continued under-representation of students of color and survey questions’ lack of meaningful context around social and cultural conditions. Members of the workgroups wanted to know directly from students what they thought of SHS questions, especially relating to mental health and youth development. This led to researchers from the CCC, Dr. Andres Lopez and Dr. Mira Mohsini, partnering with other researchers and the McDaniel High School Senior Inquiry teachers and students to hear how students understood the survey, what they liked about it, what they did not like, and their thoughts on how this survey could be more useful to them. We talk more about this process in the next section.

Statistics are consistently used as a technology of the educated elite to discuss the lower classes and subaltern populations, those individuals that are considered unknowable and untrustworthy of delivering their own accounts of their daily life.

CANDICE LANIUS (2015), "[FACT CHECK: YOUR DEMAND FOR STATISTICAL PROOF IS RACISM](#)"



It is not a question of how a person's race causes disadvantage and discrimination. The real issue is the way the society responds to an individual's racial identification.

ZUBERI & BONILLA-SILVA (2008), WHITE LOGIC WHITE METHODS, P.7



CENTERING DATA EQUITY IN OUR WORK

Survey questions are not usually written in partnership with the communities that are asked to fill out surveys. Surveys tend to ask questions from the perspective of the survey designer and/or funder, rather than the survey taker (i.e., those with direct lived experiences of the issues being researched). One of the goals of this survey modernization process was to ask survey takers – 11th graders in our case – about what questions are most meaningful and actionable from their perspectives.

To do this, we met with high school students and asked them to reflect on questions that were in the Student Health Survey. These questions were about mental health, adverse childhood experiences (ACES), and aspects of positive youth development such as volunteering. We focused on these questions because the workgroups identified them as needing improvement. We were especially interested to hear from students about how these questions could be asked better. Researchers at the Coalition of Communities of Color attended two class sessions at McDaniel High School, facilitated by PSU professors Dr. Roberta Hunte and Ari Alberg and McDaniel teachers Kate Maloney and Ian Twiss.

We started conversations with students by asking about the relationship between data and empathy. We talked about ways that data can be in the service of building empathy and how a lot of data – especially surveys and other data collection methods coming from dominant institutions – do not truly reflect experiences and contexts. We had discussions about how better data can be collected that makes experiences visible, that accurately represents different experiences, and that is transparent about how data is being used.

We gave students an optional assignment to complete on their own time and offered a \$50 gift card for completing it. Via an online survey, 82 students shared their impressions of surveys like the SHS. We asked them to review and respond to current SHS questions, which focus on adverse childhood experiences (ACEs) and mental and physical health; and we asked: what would you ask instead?



WHAT WE LEARNED

The most common reaction to the SHS was: “why don’t they just ask us how we’re doing?” All of the SHS questions were close-ended. There is no space for students to share their narratives and stories about what it’s like to be an 11th grader. All the questions focus on assessing individual behaviors at school, but don’t ask about family or community life or even experiences of going from home to school. When it came to understanding why students might miss school, they recommended the following questions to ask:

- What’s causing you to miss school?
- Do you have problems at home/outside of school?
- 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?

All of the questions that students would like to see on a survey ask about context. These questions invite students to tell their stories, and it is in these stories that we learn what needs to be done to improve or change conditions.

WHAT WAS ACCOMPLISHED

The overarching recommendation from this process – and a necessary strategy for data equity – is that the community must play a central role in leading and providing input into survey design, data analysis, and communication of findings. OHA, and more specifically, PDES, took on this recommendation by creating a Youth Data Council (YDC) to give input (and ultimately collaborative decision making) into the design, content, and dissemination of the 2022 Student Health Survey (SHS).

I always think about the data as story, and each person who contributed to that data as storytellers. What is our responsibility to the story and our responsibility to the storyteller? Those are all indigenous concepts, that we always care for our storytellers, and we always have a responsibility to our stories.

ABIGAIL ECHO-HAWK (2019),
"ABIGAIL ECHO-HAWK ON THE ART
AND SCIENCE OF 'DECOLONIZING
DATA'"



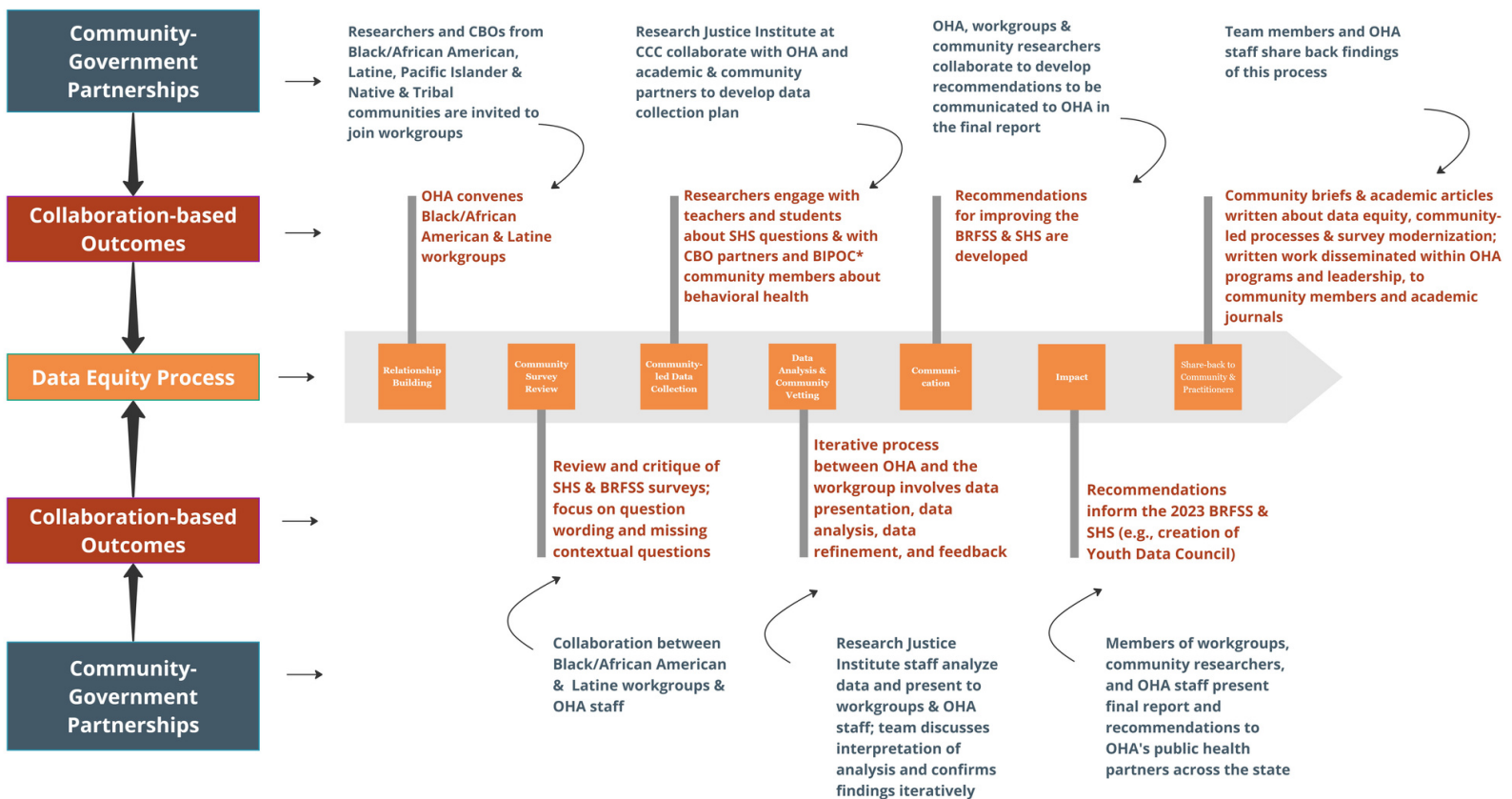
For more information about data equity and justice, visit the Research Justice Institute's website:

[BIT.LY/RESEARCHJUSTICEINSTITUTE](https://bit.ly/researchjusticeinstitute)

More information about the YDC can be found [here](#). Other data equity strategies, many of which surfaced during our work together, are being included in the SHS process. These include:

- Collecting better disaggregated data on race, ethnicity, language, disability, sexual orientation, and gender identity
- Working with YDC to revision and revise the Positive Youth Development questions to be trauma-informed, conceptually integrated, and focused on root causes
- Minimizing the burden on youth by shortening all the questionnaires
- Including the Everyday Discrimination Scale ([short version](#))

FIGURE 1: MODERNIZING THE BRFSS AND SHS THROUGH A DATA EQUITY PROCESS



*Black, Indigenous, and people of color