MODERNIZING A BEHAVIORAL HEALTH SURVEY
THROUGH A DATA EQUITY PROCESS

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 health data via the Behavioral Risk Factor Surveillance System (BRFSS). 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 Student Health Survey (SHS)* 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 BRFSS).

The primary authors of this brief are Dr. Roberta Hunte (Portland State University) and Dr. Mira Mohsini (Coalition of Communities of Color), 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
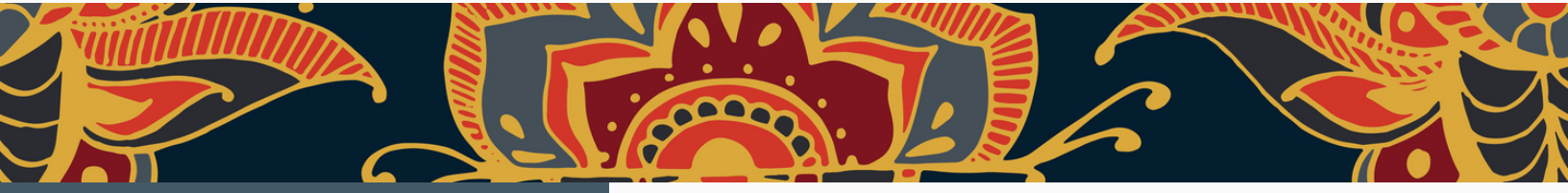
> "...statistical methods themselves encode particular assumptions which, in societies that are structured in racial domination, often carry biases that are likely to further discriminate against particular minoritized groups."

DAVID GILBORN (2010), "THE COLOUR OF NUMBERS: SURVEYS, STATISTICS AND DEFICIT-THINKING ABOUT RACE AND CLASS" P.254

BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM (BRFSS)

The BRFSS is part of a national survey and is partially funded through the Centers for Disease Control. Funding for some state public health programs comes from the findings from the BRFSS. Every few years Oregon conducts a racial and ethnic BRFSS oversample to ensure that sufficient numbers of Black, Indigenous, and People of Color (BIPOC) communities are included in the study. This survey is administered via phone.

DATA EQUITY CONSIDERATIONS FOR BRFSS

In engagement with community members and members of the project team it emerged that data equity is vital to improving the BRFSS as the lack of broad participation of BIPOC communities has reduced the usefulness of the surveys. The BRFSS is primarily conducted as a landline survey. The primary respondents have been older white people. Key issues that emerged as challenges with the BRFSS include survey length, high implementation costs, limited participation for smaller geographic areas, concerns about representation, and lack of community engagement in survey design, analysis, interpretation of results, and dissemination of findings. Responses to survey questions generate data that is used to target services, secure grant funding, address emergent health issues, inform proposed legislation, and measure progress toward public health objectives.

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 the Oregon Healthy Teens Survey 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 BRFSS survey including continued under-representation of communities of color and the limited contextual questions that could explain quantitative findings.

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 members of different communities of color how they understood the BRFSS findings from their communities and their thoughts on the questions being asked.

To do this we reviewed the survey questions that were already in the BRFSS and identified their shortcomings as well as areas where more data is needed. With community members we co-constructed a different survey on behavioral health that centered the needs and desires of BIPOC communities in Oregon. The first iteration of this survey was developed in collaboration with a steering committee convened by the Research Justice Institute at the CCC for their statewide behavioral health research (the CCC's final report can be downloaded here). The steering committee consisted of community members, leaders, and activists who have deep expertise and lived experience with Oregon's behavioral health care system. The survey questions developed with the steering committee were then presented to the two workgroups for feedback.

"There are a variety of reasons for the lower participation rates of ethnic minority groups in research, ranging from mistrust and fear of the medical establishment, and stigma related to research participation, to exclusion by design."

HANNAH E. KNIGHT, SARAH R. DEENY, ET AL. (2021), "CHALLENGING RACISM IN THE USE OF HEALTH DATA"

"If trusted people are not collecting data within communities, the likelihood of distrust and refusal to share information is high. On the other end of the cycle, a major gap exists in data analysis. Without relevant lived experience, the risk of misinterpretation of data or making false assumptions is high."

GINGER ZEILINSKIE AND LINDSEY B. GOTTSCHALK (N.D.), "THE VOICES WE TRUST: BUILDING EQUITY-CENTERED COMMUNITY DATA ECOSYSTEMS THAT WORK FOR EVERYONE" P.13

Due to this process, we were able to ask questions that were culturally meaningful and sensitive and that asked community-focused questions about behavioral health, rather than individual-centered questions that are typically included in surveys like the BRFSS. For the survey dissemination phase, both steering committee members and work group members helped circulate the survey among BIPOC communities throughout the state. During the analysis phase, data was vetted and confirmed by the steering committee and work groups. It was through this community-centered process that we demonstrated how data equity is critical for ensuring that research via surveys is reflective of BIPOC community needs and desires.

WHAT WE LEARNED

In engaging with community partners we learned that the questions asked and the conclusions drawn from the BRFSS survey did not match how communities experienced themselves. Critiques of current approaches to collecting BRFSS data include:

- Survey results lacked a meaningful context for action; Survey questions focused more on individual behaviors not social or cultural conditions influencing actions.
- Intersectionality is important to engage in the research process as people live complex lives with multiple overlapping identities; disaggregating data by race, ethnicity, income, age, primary language and country of birth is a first step.
- Survey questions need to yield results that can be actionable in policy terms.
- The low BIPOC survey response rate is a sign that the way the survey is distributed is problematic; BIPOC communities do not respond in high numbers to anonymous phone call surveys.
- To contextualize the findings of BRFSS other data sources must be integrated in the analysis.
- Translation and the wording of some questions needed to be changed to improve understanding of the questions and issues raised in the surveys.

The community constructed behavioral health survey focused on communities of color and was circulated statewide. Some of our learnings included:

- Behavioral health needs for individuals are different than needs identified for the community. For instance, having access to fun and stimulating activities is an important individual need; having access to advocates and guides who can help with navigating the healthcare system is an important community identified need.
- Many BIPOC respondents seek behavioral health care from non-dominant sources, like religious figures, cultural organizations, and traditional healers.
- Top barriers to accessing behavioral health care services are lack of awareness about services and lack of culturally and linguistically specific providers.
- Many BIPOC respondents shared experiences of medical discrimination. The main reasons why providers are experienced as untrustworthy included lacking empathy, harmful care practices, and experiences of being stereotyped.

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 is currently working with public health to pilot some different methods of survey data collection that are informed by and developed in partnership with different stakeholders.

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.

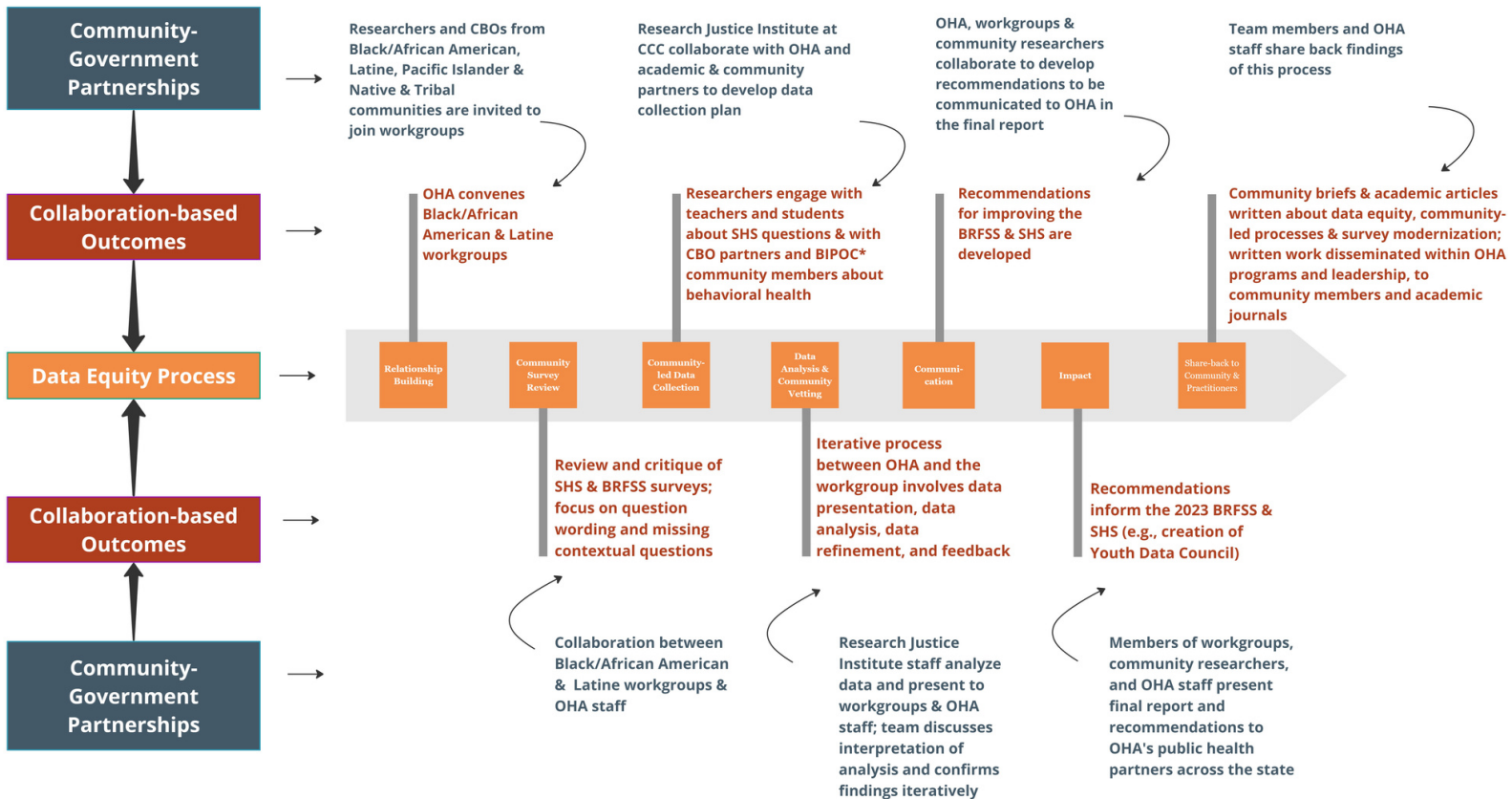ABIGAIL ECHO-HAWK (2019), "ABIGAIL ECHO-HAWK ON THE ART AND SCIENCE OF 'DECOLONIZING DATA'"

For more information about data equity and justice, visit the Research Justice Institute's website:
BIT.LY/RESEARCHJUSTICEINSTITUTE

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

Community-Government Partnerships

Collaboration-based Outcomes

Data Equity Process

Collaboration-based Outcomes

Community-Government Partnerships

Researchers and CBOs from Black/African American, Latine, Pacific Islander & Native & Tribal communities are invited to join workgroups

Research Justice Institute at CCC collaborate with OHA and academic & community partners to develop data collection plan

OHA, workgroups & community researchers collaborate to develop recommendations to be communicated to OHA in the final report

Team members and OHA staff share back findings of this process

OHA convenes Black/African American & Latine workgroups

Researchers engage with teachers and students about SHS questions & with CBO partners and BIPOC* community members about behavioral health

Recommendations for improving the BRFSS & SHS are developed

Community briefs & academic articles written about data equity, community-led processes & survey modernization; written work disseminated within OHA programs and leadership, to community members and academic journals

Relationship Building	Community Survey Review	Community-led Data Collection	Data Analysis & Community Vetting	Communi-cation	Impact	Share-back to Community & Practitioners

Review and critique of SHS & BRFSS surveys; focus on question wording and missing contextual questions

Iterative process between OHA and the workgroup involves data presentation, data analysis, data refinement, and feedback

Recommendations inform the 2023 BRFSS & SHS (e.g., creation of Youth Data Council)

Collaboration between Black/African American & Latine workgroups & OHA staff

Research Justice Institute staff analyze data and present to workgroups & OHA staff; team discusses interpretation of analysis and confirms findings iteratively

Members of workgroups, community researchers, and OHA staff present final report and recommendations to OHA's public health partners across the state

*Black, Indigenous, and people of color