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# Modernization of Public Health Survey Systems:

## Community Engagement & Innovative Science - Progress to Date



October 31, 2022

Oregon  
**Health**  
Authority

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# Overview of Today's Presentation

- Brief summary of survey modernization project results and changes being implemented
  - Collaboration with communities
  - BRFSS innovative methods pilot study
- Pulling it together - new model of survey systems
- Questions and discussion

# **Brief summary of survey modernization project**

# Behavioral Risk Factor Surveillance System (BRFSS) is...

- Sponsored by the Centers for Disease Control & Prevention
- Telephone survey of adults in Oregon
- Part of national survey
- Range of topics: risk and protective factors, prevention/screening, health outcomes, demographics
- Every few years, a racial and ethnic oversample is conducted

# Challenges with BRFSS

- Lack of community engagement
- Lack data for Pacific Islander communities
- Concerns about representativeness and validity of data
- Survey length
- Expensive
- Changing needs

# Oregon's Youth Survey – the Student Health Survey (SHS) is...

- School-based, anonymous and voluntary health survey of 6th, 8th and 11th graders.
- Collaborative effort between Oregon Health Authority (OHA) and the Oregon Department of Education (ODE).
- Questions about student health & safety, mental & behavioral health, school climate & culture, impact of COVID.
- Historically, rooted in two separate youth surveys – Oregon Healthy Teens (OHT) and Student Wellness Survey (SWS), focused on physical and mental health respectively.

# Challenges with SHS

- Lack of community (youth & adult) engagement
- Survey length
- Changing needs
- Lack of contextual data raises concerns about validity
- Concerns about representativeness

**Collaboration with communities**



**Identification of innovative statistical & survey methods**



**Solutions**





# Collaboration with communities

# Collaboration with Pacific Islander communities

- Strengthened existing and created new partnerships, expanded on previous work
- Funded Pacific Islander researchers, individuals, and community organizations to build capacity.
- Core team of Pacific Islander researchers and PDES research scientist
  - Oregon Pacific Islander Coalition (OPIC) played advisory role and oversaw data sovereignty process
- Co-designed approach, data collection methods and tools, and participatory analysis process
- Co-wrote final report and recommendations

# **Collaboration with African American and Black, Latinx, and American Indian/Alaska Native communities**

- Developed and funded 3 community data project teams
- Conducted participatory analysis of BRFSS & Oregon Healthy Teens Survey
- Community-led data collection on topics and methods of their choice
- Co-developed reports that summarized project team recommendations

	<b>Participatory analysis</b>
Community engagement	Yes
Data for Pacific Islanders	No
More representative	Provided essential context for understanding the limitations inherent in a survey not designed by the communities it is meant to survey.
More valid data for BIPOC communities and data that align with community priorities	After the fact participatory analysis of survey that community did not co-design validates the limitations of the generalizability of that data.
Less expensive per complete	Short term – No; Long term - Possibly
Shorter survey	NA
Sensitive questions	Able to provide important context for interpretation of sensitive questions

	<b>Comprehensive community-led approach</b>
Community engagement	Yes
Data for Pacific Islanders	Yes
More representative	More than BRFSS, but could better represent more diverse PI ethnic groups
More valid data for BIPOC communities and data that align with community priorities	Community partners say (enthusiastic) yes
Less expensive per complete	Possible
Shorter survey	Yes
Sensitive questions	Yes
<b>Builds/strengthens community capacity</b>	<b>Yes</b>
<b>Communities have ownership over data and how they are reported, so trust results</b>	<b>Yes</b>
<b>Strengthens relationships and builds trust between OHA and communities</b>	<b>Yes</b>

# Key Lessons Learned

- Scientific integrity is compromised without community engagement - validity, relevancy and generalizability
- Questions focused on individual behavior without context perpetuate systemic disparities
- Design questions that result in data that are actionable and drive program & policy change
- Equity needs to be a starting point for survey design rather than being driven by siloed programmatic needs
- Community engagement is needed at every step of the process from design through analysis and reporting.
- Data justice – fairness in the way people are made visible, represented and treated as a result of their production of digital data (Taylor, 2017)

# General Recommendations

- Public health survey methods must be revamped
- Integrate long-term, compensated community engagement at every step from design to dissemination
- Allow sufficient time and resources for relationship building
- Fund communities directly and sufficiently
- Build capacity among community organizations & members
- Build internal OPHD staff capacity
- Share power and be transparent
- Be flexible and willing to recognize mistakes and change course
- Avoid overburdening community partners

## Where we are now – Fall 2022.

- Developed three reports – OPIC, CCC, and NPAIHB
- Disseminating findings through presentations
- Disseminating findings through written products
- Established Youth Data Council (YDC) to increase youth voice in the development of the SHS.
- Re-evaluating SHS and implementing community recommendations
- Working with OHA leadership and programs to plan for BRFSS



# Working with OHA Leadership

- Vision for the need for data equity.
- Build division-wide commitment and infrastructure for sustained collaboration.
- Division-wide assessment and coordination of community engagement activities.
- Training & technical assistance
- Flexible contracting and funding mechanisms that support sustained partnerships.

# Community Collaborators

## Oregon Pacific Islander Coalition

- Maria Dizon, Filipinx/lived in Saipan
- Virginia Luka, Palauan/lived in Guahan
- Alyshia Macaysa, Native Hawaiian, Filipinx
- Natlie Dutro, Native Hawaiian
- Siiri Visto, Native Hawaiian
- Adri Jones, Filipinx
- Kianna Angelo, Marshallese
- Jonathan Cruz, Native Hawaiian
- Bella Borja, CHamoru
- Dr. Jacinta Galeai, Samoan
- Elizabeth Paulson, Samoan

# Community Collaborators

## NPAIHB/Northwest Tribal Epi Center

- Bridget Canniff  
Project Director, Public Health Improvement & Training (PHIT)
- Kimberly Calloway  
Project Specialist, PHIT
- Kerri Lopez  
Project Director, Western Tribal Diabetes and NW Tribal Comprehensive Cancer Projects
- Natalie Roese  
Contractor

## Tribal Work Group

- Nicole Barney  
University of Oregon/Klamath Tribes
- Pamela Gutman  
Cow Creek Tribe
- Jessica Hamner  
Coquille Tribe
- Obinna Oleribe  
Klamath Tribes
- Richie Thomas  
University of Oregon

# Community Collaborators

## Coalition of Communities of Color:

Dr. Andres Lopez, Research Director

Dr. Mira Mohsini, Senior Researcher

## Latinx Project Team:

Dr. Lorraine Escribano, Director of Evaluation, Latino Network

Roberto Gamboa, Operations Manager, Euvalcree

Dr. Daniel Lopez-Cevallos, Associate Professor, OSU

Claudia Montano, Projects Manager, The Next Door, Inc

Karla Rodriguez, Community Health Worker, Oregon Latino Health Coalition

## Black/African American/African Immigrant & Refugee Project Team:

Dr. Roberta Hunte, Assistant Professor, Portland State University

Oluchi Onyima, formerly of Urban League

Sherly Paul, Community Health Nurse, Multnomah County Healthy Birth Initiative

Dr. Ryan Petteway, Assistant Professor, OHSU-PSU School of Public Health

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**Identified  
innovative  
statistical &  
survey methods**

# BRFSS Pilot

- Assessed the field for knowledge
  - Literature review: survey methods and reports
  - Key informant interviews: survey experts, general and specific
- Collaborated with survey methods experts to plan
  - Dr. Don Dillman, internationally-recognized methods expert
  - Director of California’s Health Interview Survey Todd Hughes
  - OR Public Health Division surveillance experts
- Fielded a “proof of concept” methods pilot during fall 2020
  - Address-based sample
  - Progressive 5-step recruitment communications strategy
  - \$2 cash incentive with letter #1 from Oregon’s health officer
  - Respondents choose online, print, or phone response

# 5-step BRFSS Pilot Recruitment

## 1: Letter

- Invitation with \$2 bill, person with most recent birthday asked to complete survey
- Website with unique ID to use online; toll free phone #

## 2: Postcard

- Reminder to take survey, online and toll-free phone information

## 3: Letter

- Print copy of survey with prepaid return envelope
- Online & toll-free phone information

## 4: Card/Letter

- Randomized: 2nd print copy OR reminder postcard
- Online & toll-free phone information on both

## 5: Phone call

- Phone call to # linked to household
- Left reminder messages OR conducted survey if desired

# Key Results

- “Proof of concept” methods findings: **it worked**
  - 36% response rate (vs. 5-8% BRFSS standard)
  - Multiple, progressive attempts continued to generate responses (12% came in after phone calls in attempt 5)
  - People prefer non-phone response (59% online, 36% print, 5% phone)
- Quality of data measures
  - Less missing data vs. standard BRFSS for some sensitive measures
  - For outcomes, most “core” measures look similar to BRFSS after adjustment
  - Open-end questions gave people a chance to share in their own words
- Potential value, not yet tested
  - Opportunities for focused data collection, potentially in partnership with communities (geographic oversampling, integrating community sampling frames)



	<b>BRFSS pilot with address-based sampling</b>
Community engagement	No, but this is quite possible (BIPOC, local health)
Data for Pacific Islanders	No, but could oversample by geography and/or integrate community-centered sampling/data
More representative	Unclear, but higher participation rates overall; lower in rural counties, ages 18-29, Spanish speaking adults
More valid data for BIPOC communities and data that align with community priorities	Unclear, but higher participation rates, including for online response; community stakeholder feedback positive; potential for combining data with community-centered samples (could tailor to community needs)
Less expensive per complete	Yes: vendor costs about \$54/complete (larger sample cost-efficiencies could reduce to \$40), vs. \$50-65 standard/\$500 oversample
Shorter survey	Not in number of questions, but design and self-selected modes reduce respondent burden; participant self-reported timing was shorter
Sensitive questions	Yes; also allowed open-end question formats to give people freedom to use their own words

# Initial steps: State BRFSS

Goals for modernized state surveys are to align with/support community-centered efforts/needs, be sustainable, and stay nimble to adapt to evolving methods

- **Reach:** share pilot findings with OHA and external partners (e.g., CDC, research literature)
- **Engage:** Support community/state partnerships like participatory analyses, “better BRFSS” questions
- **Mobilize:** Early to mid-2023: discuss idea for integrated Oregon BRFSS similar to CHIS model
  - Keep minimal “CDC core”
  - Replace “state form” using state discretionary funding with BRFSS pilot methods, fielded quarterly
- **Implement:** “integrated BRFSS” in 2024

# **Pulling it together - new model of survey systems**

**Collaboration with communities**



**Identification of innovative statistical & survey methods**



**Solutions**



# Draft initial framework for state adult survey system

- **Federally funded population-based surveys** to monitor core public health measures (e.g., Core BRFSS, Pulse Survey)
- **State BRFSS** that improves on Core BRFSS methods based on community recommendations, BRFSS pilot, and scientific research
- **Community-led data collection models** for specific community needs and priorities
- **Complementary surveys** that are quick to implement and less expensive (e.g., panel surveys, Facebook surveys)
- **Other existing data sources**

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# Community-led data collection models

- With Epidemiology and Laboratory Capacity (ELC) grant, we are planning to provide \$1 million to BIPOC communities to develop community-led data systems:
  - To assess broader impact of pandemics using the State Health Improvement Plan framework (e.g., effects on economic well being & behavioral health)
  - Hope is these data systems will provide information on community strengths and vulnerabilities, so we can consider equity effects of our potential responses
  - One goal is for these data systems to inform SHIP
- Priority-setting will be done by community representatives

# Questions?



## Questions for discussion

- How do you use the BRFSS data?
- How do you use the SHS data?
- What strengths & limitations do you see?
- What are the challenges to using the data?

## Questions for discussion

- What other data do you use?
- What other data do you need?
- What types of data do you want to collect?

## Questions for discussion

- What do you think about the proposed framework for the adult survey system?

## Questions for discussion

- If/how would you as a LPHA or CLHO like to be engaged in these conversations going forward?

# Thank You!