

**Public Health Advisory Board (PHAB)
Strategic Data Plan Subcommittee
June 15, 2021
DRAFT Meeting Minutes**

Attendance

Subcommittee members present: Eli Schwarz, Alejandro Qural, Veronica Irvin,

Subcommittee members absent : Gracie Garcia, Dr. Hemmings, Eva Rippeteau, Hongcheng Zhao

Oregon Health Authority (OHA) staff: Cara Biddlecom, Marjorie McGee, Diane Leiva

Welcome and Agenda Review

Diane Leiva (OHA)

Introductions and brief review of agenda. The focus of today's meeting will be to reflect on the three documents outlined in the agenda:

- White Supremacy and the Core Functions of Public Health
- Public Health Survey Modernization Presentation
- Health Equity Review Policy and Procedures

Meeting Minutes

(All)

Question was raised as to the action items of the previous meeting and whether they were reflected in the minutes.

Eli - Specifically, how to engage community-based organizations to improve data quality. Perhaps OHA can list the organizations we would like to contact and get them engaged. The need to invite agencies outside of OHA, e.g. Oregon Department of Transportation, Oregon Department of Education.

Veronica - Some of the questions raised were what forms of information have already been gathered and whether there have been any updates. This request has been noted and will be followed up prior to the next meeting.

Marjorie – various parts of the agency have connections with the BIPOC community and the Coalition of Communities of Color. My strong feeling is alignment so that we don't have different parts of the agency connecting with BIPOC communities and not knowing what the other parts of OHA is doing. I look forward to tightening our alignment in the internal work we are doing in OHA.

Diane will follow-up with the internal team on contacts for agencies outside OHA. We also ask subcommittee members to provide any contact information they have available.

Veronica inquired on whether we will be reviewing the charter.

Diane - We will review the charter, make changes, and readdress the deliverable. The only part that has changed is the timeline. That will be changed focusing more on milestones instead of dates.

Minutes of the May 18, 2021 meeting were approved.

Equity as the foundation of a Strategic Data Plan

(All)

Cara – in order to start to approach a plan (dates, goals, objectives, milestones), and referring to engagement as it relates to Health Equity Review Policy and Procedure for the PHAB, and community engagement broadly on this work, the presentation at the last PHAB meeting from our partners on Survey Modernization, as well as the article on White Supremacy and Core Functions of Public Health, together with our own learning and development during the last few months, how do all of those things frame the strategic data plan and what the product might be? How does this work move forward based on what we heard last month on survey modernization and dismantling aspects of white supremacy

on how we do public health data which leads to programs and policy? This is an open conversation as to how this leads to next steps for this Subcommittee.

Cara? - Review of the White Supremacy article – We cannot talk about public health in isolation. We need to consider other factors and stressor communities of color experience.

Veronica – Discuss how the paper bucketed the assessment. Who is using the data? If we are talking about stressors such as police brutality, are these questions appropriate to ask in a telephone format? Is this a triggering question? Is this a question the community wants to be asked in this format and how will this data be used?

Diane – Echoing Marjorie’s suggestion at the Internal Team Meeting about having people from the BIPOC community involved in these conversations. They will inform how questions need to be asked and framed. As Dr. Hemmings noted, until you are able to engage communities and build that relationship and that trust, that is the foundation and starting point of these conversations. As far as policy development, how do we communicate effectively.

Veronica – Moving data collection outside government agencies and toward community partner organizations and CBOs, and pros and cons of that. That would build trust and ensure adequate representation. From a methodological point of view, make sure it is standardized across groups as best you can. When we are talking about this subcommittee, are we talking about re-mapping the BRFSS or totally starting from scratch? What are we keeping? What are community groups already doing?

Diane – One of the points made in the Survey Modernization presentation is actionable items. It is in that process that relationships are built, and trust is gained. Participatory. We also discuss what we can do right now. What resources are available?

Veronica – Bringing up the PHAB meeting from May, there was support for moving toward these questions, but that this would also increase the length of the survey. Really thinking what we want to focus on. How do we replace one

question with others that do represent more strategies and more ways for improvement, but will take more time? Do we pair down the main topics for each wave of the survey and data collection mode or do we dive into certain inequities and what could be factors or strategies to use for those?

Diane – One of the points that came up at the Internal Team meeting as well as at the Data Decolonization meeting is that we still have federal and state reporting that needs to be done and cannot be paused. How to integrate what we are learning now and what we are getting from the community into that data?

Survey Modernization Presentation – action items reviewed.

- Key Themes –
 - Sample size
 - Survey translation and health literacy
 - Lack of Meaningful context
 - Questions need to be actionable
 - Integration of other data sources
 - Intersectionality
- What we can do...
 - Center community data and strategies for self-determination (empowerment versus autonomy)
 - Let communities of color frame how mainstream data fails to represent them
 - Help local and regional entities with community led question development, data collection strategies, data analysis and data use.
 - Connect available mainstream data to community data (led by the community).
 - Establish decision making processes that defer to the community.

Eli – As an end user of BRFSS, PRAMS (Pregnancy Risk Assessment Monitoring System) and a number of surveillance programs, we have heard from the COFA (Compact of Free Association) population. We have had them at the PHAB twice. Once as the BRFSS group that was using the COFA population as an example of how the BRFSS was incomplete, but for those of us that have been involved with OHA in their attempts to identify disparities sensitive data and metrics, it has been clear for some time that the data we are collecting is not as good as we would like it to be. I think we need to think why are we doing all these surveillance programs? We have more than 100 surveillance programs just in Oregon and many are CDC directed. Much of this information is put together for the Healthy People 2030 with certain objectives that we are trying to achieve. All

these programs have an objective and most of them are used to convert to policy. The policy may not always be ideal. But if we imagine everyone does their own thing, the Native Americans were collecting data one way and COFA another way and White Supremacists still another way, there would be no standardization, but everyone would be happy with the data they collected themselves. But it would be useless. We need to find balance on the useful way to collect. I am in favor of engagement from the groups we heard from at the PHAB meeting which was informative and useful. There is a lot of resources to provide us with information about what is an acceptable way to ask certain questions. Questions that are very sensitive and those less sensitive that can easily be collected. Over the years, the main problem was that the basic demographic information was not available. If we don't have that information available, there is no way to stratify any other information that we are collecting. We need to identify how we get this information included in our data collection systems. As far as I can see, what we talked about last time is why I raised it again. The quicker we can get engagement from the groups who are looking to identify what questions and methods we can use, the quicker we would arrive at some constructive results. Before we break up all the surveillance programs that we have because they are white supremacist or racist, we will potentially lose a lot of information if we do it without replacing it without some relevant alternative.

Marjorie – Three things came up. We do a lot of surveillance and data collection, but I wonder how useful it is at identifying inequities. I have a deep background in disparities generally but also specifically around disabilities. One of the things with disability efforts is that they are not what the politically organized disability community would support. The research questions and the data collection has been framed by non-disabled people with a certain mind set –disability is bad, we have to prevent it, and how do we do that – instead of creating more positive, affirming value with people with disability. Thus, my comment in the chat that yes, we have a lot of surveillance, do the communities see value in it? Are the research questions coming from outsiders that are not experiencing? It is usually people with privileged identities and dominant cultural perspectives that design all of this and it is the way we have done this for years. This is the case with the BRFS. Even though we have telephone technologies, why are we still doing this

on the phone?

The other perspective is PREPARE, which is a model of social determinants of health questions many of the health care providers and FQHCs have adopted. It streamlines and provides consistency in asking about social determinants of health. How do we get it more consistent? I am hoping House Bill 3159 (Relating to Data Collection: Requires CCOs and health care organization to collect REAL-D data) passes. Some of the resistance to adding all the REAL-D questions is that they do not want to expand the length of the survey. House Bill 3159, if it passes, calls for the creation of a REAL-D SOGI Registry where data can be uploaded directly into the registry and can be part of an EHR system. If that happens, that means we can redo some of the length of the different surveys and at the same not lose some of the REAL-D SOGI demographic information. I think Eli's questions and concerns were spot on.

Eli – What Marjorie highlights is extremely important, and stresses attempts that have been made. I recall the BRFSS had a specific Medicaid version. Because Medicaid members are not captured in the regular BRFSS or, where they appear, sample size is a problem because we don't get a representative sample size of Medicaid and how they are faring? The first time I heard that I had just come back from a CDC meeting where they were using a specific statistical method to identify small populations. I think it was the small sample statistical method where they were able to impute based on a relatively small sample to a much larger population and it had a very high statistical significance meaning. I do think we have methods where it would be possible to target versions of the BRFSS with a small core of common questions and other parts of the survey targeted toward particular populations and they could be heavily engaged in identifying questions that would be relevant for that group. One of the things we learned from the COFA population discussion was that we can never have a normal sample where the COFA populations appears in reasonable way. That means we would have to come up with a survey where they would be highlighted. These are things that we need to include in our strategy.

Public Comments and Questions

(All)

No questions and/or comments from the Public.

Health Equity Review Policy and Procedures

(All)

Review of the documents and questions posed in the document.

Veronica – One of the goals of the PHAB was that any discussions or decisions made included thoughts around health equity, inclusion and racial equity and its implications. We tried to create these questions to reflect when people come to present and before we make decisions. It was launched about six months ago. Most of our presentations have been squarely related to this so we haven't gone through the process of asking these questions because the topics of the presentations were on this. The topics of the presentation were on racial disparities and vaccinations. When we start talking about funding priorities, we may use this again to make these decisions.

Alejandro – I think Veronica's point is critical in terms of making decisions and moving forward. We are really trying to understand the impact of the decisions that are outside the boundaries of public health and the areas that public health touches. From the social determinants of health, research on this is really broad in scope. These set of questions help us assess and step outside the direct issues related to public health services.

Reflections – How does Alejandro's point tie with the first article that we discussed –the core essential functions of public health? What is the common thread in the material that we discussed? Engagement, trust, building relationships. What is the next step? Is it to reach out to Community-based Organizations and state agencies to see the work that they are doing so that we start building that foundation? Do we need to start the conversation with health or is health an outcome?

Cara – For PHAB members who were at our last meeting, we will be anticipating the final reports and recommendations to be shared with us from our Survey Modernization partners. One thing we have been talking about is how we can take the strategic data plan as a way to help advanced those recommendations

that are community led and figure out how to have conversations together about how to do that with all our subcommittee members, PHAB, and our community partners. We are trying to see what works for them as far as being able to participate after the final reports are put together. That can be some framing on what we do and we also think of the scope of public health data -- there may be places that are ready for focus right now and maybe there are some places that focus on the REAL-D component.

If you would like these minutes in an alternate format or for copies of handouts referenced in these minutes, please contact Lisa Rau at lisa.k.rau@dhsosha.state.or.us. For more information and meeting recordings please visit the website: healthoregon.org/phab