

**Public Health Advisory Board (PHAB)
Strategic Data Plan Subcommittee
May 18, 2021
DRAFT Meeting Minutes**

Attendance

Subcommittee members present: Eli Schwarz, Dr. Hemmings, Veronica Irvin, Hongcheng Zhao

Board members absent : Gracie Garcia, Alejandro Qural, Eva Rippeteau

Oregon Health Authority (OHA) staff: Cara Biddlecom, Kirsten Aird, Diane Leiva

Welcome and Agenda Review

Diane Leiva (OHA)

Diane shared that today's meeting will be on changes to our charter and ground the conversation on equity. There have been lots of changes related to equity and what data assessment means and how to move forward with equity and justice, using that framework to develop the strategic data plan. We will start discussion with PHAB's Health and Equity Policies and Procedures. The focus will be the types of values and approach we want to take. What a strategic data plan looks like moving forward with equity and justice. What we need to engage consistently and in a feedback loop with community on how we develop the plan and what the outcomes are and what that means.

We will probably have time for our public comment, so public members joining us today, thank you.

Meeting Minutes

(All)

Correction needed Meeting Minutes to spelling of Veronica's last name (to Irvin). Minutes of the last meeting were approved.

Subcommittee Charter

(All)

Review of the changes that were incorporated into the charter based on previous meetings feedback. In relation to the stakeholder question on whether they are needed or not, we need to focus on what types of questions need to be answered. As well as, what are the mile markers, what are the questions and who do we need to ask? For example, the questions posed in the Health Equity document addresses how we need to think when drafting this plan. What types of conversations do we need to have with communities and with each other?

Eli – indicates that when looking at stakeholders, health centers and clinics and hospitals, FQHC are not the totality of health care providers. Suggestion to change those to Healthcare Providers.

Reference is made to two types of stakeholders. Those who are purveyors of data and those who are end users. How do we reach out and engage them? For hospitals, outreach could be with the Hospital Association, but that from the data perspective. But who produces the data and how it's being used is the question? Mention on Data Justice and a strategic data plan and who should be the voices in the strategic data plan.

Health Equity Review Policy and Procedures

(All)

Review of the document. Kirsten indicates if the deliverable for us is a plan of action with key strategies and tactics of how to better collect, analyze and report data and create an understanding of ownership of that data with the end of community empowerment and community health; then the questions in the Health Equity Plan are relative to how does data collection and/or analysis, and reporting of data contribute to racial justice, rectify past injustices, differ from current status, support individuals in reaching the full health potential. It is in the frame of the processes around data to get it into the right hands with the right information to make change. That would be the end-product of the plan. It will help guide us. What steps, criteria, actions, and strategies that we, as a public

health profession, need to get to, to have a different state of data collection, analysis, and reporting.

Dr. Hemmings – notes that nowhere does it say that this data will be used to prevent inequities from happening in the first place. It addresses, rectifies, but do we also hope that this data will help drive change to the point where we prevent inequities from even happening.

Veronica – When we were drafting these questions, we were using language that could be used for multiple documents. I think for the data deliverable that we work on we need to have something that explicitly states around Dr. Hemmings’ statement on rectifying and improving. Maybe it needs to be clearer in this document.

Eli – At the moment, the data we collect is incomplete. A fair analysis or policy statement in relation to deliverables. We need to have assurance that the data we are working with is representative and as complete as possible. These variables in item #5 are extremely sensitive and there is a considerable portion of the population that doesn’t want to provide this information for those who are collecting the data. Whatever we collect, as far the analysis, will be faulty. Unless we can improve our data collection systems, our data will not be good enough to ensure work against inequities or toward equities.

Dr. Hemmings – That is where working with and involving the community that you are trying to get the data from comes into play. To build that relationship with the community for them to trust that if they disclose this information that is going to be used in a way that is going to benefit them.

Eli – We have been discussing this issue. We had subcommittee with OHA, Metrics and Scoring, and Health Policy Board and we stopped short of our conclusions because OHA said that we are not able to produce the data that you want. Until we get our IT system set up to collect data in a reasonable way, we are not to do this. It seems like we are going in circles.

Diane – The keyword is trust. The reason we have had success with Community-based Organizations is that we have had a level of trust between the Community-

based Organization and the people in that community. People do not want to report on their age, religion, or race because it may give them a visibility that is not beneficial to them so they would rather opt out.

Dr. Hemmings – You must factor that in within the context of any community but particularly in Oregon with the historical injustice that has existed and the foundations in which the state was formed within that context. You must invest in that community-based relationship building before you get to the data collection process. I am unsure how much we want to invest in that piece because we are very quick to want to collect that data.

Hongcheng – Even before we can talk about how we can collect and analyze; do we need to do a data inventory first? Do we have any real data sitting there? There are two problems. Health centers and hospitals have rich data so how can we have access to that data? Lots of ownership problems. We can address that to have access to that data. Additionally, there are community-based organizations. Their IT systems aren't as advanced as hospitals and health clinics. We need to look at their data and the data structure before we can move on to all the categories of data collection, analysis and reporting and the value added.

Diane – Thank you, Hongcheng. The question that comes to mind, echoing what Dr. Hemmings noted is how are we going to prevent those inequities? Some of the data is good and some of it may be deficient. Referring to Eli's comment in the last meeting quoting Dr. Sidelinger, only 40% of Public Health data is racially representative. We know that there are health inequities, so do we part from the premise that the data is incomplete and is biased and is this the conversation that we need to have with the community as a way of starting to foment that trust?

Hongcheng – The issue of health inequity is extremely important. The underinvestment of infrastructure in communities of color, there is a lot of work. Having racial equity in policy.

Diane – one of the key strategies that has come out of this conversation is improve data collection systems.

Hongcheng – Need to recognize the underinvestment of the infrastructure in communities and acknowledge that. We need to invest before we structure the data for public health. Otherwise there is a huge missing link. What can we do to address that?

Eli – how able is an organization like OHA to have conversations with a broad base of community organizations. Is there a list of organization that send out policies for public hearings from those organizations that Rosemarie was talking about? Or, do we need to identify which intermediaries we need to connect with to reach those different communities?

Kirsten – a data inventory across OHA is something that we have and are updating particularly due to COVID. But basically understanding of the landscape of what kind of data we collect with all of its imperfections and what data we recently collect from Community-based Organizations and to your point, Hongcheng, recognizing that it is a challenged infrastructure that hasn't had the investment put into it to adequately do something. That is something that is in process that we want to get in front of this group. Before addressing Eli's question on OHA's capacity getting back to Rosemarie's point that it is about trust. As we think again about the key elements of where we start, because this isn't about starting at a perfect place on trust and data. We aren't going to start there when we start this plan. This plan will help us get there. What is hard about collecting data is trust and community. That is their data to own or that it is there data to report on. Or that the community would have the trust to give us any of this information. I heard that what is hard about collecting data is local infrastructure and resources for the people that are interested in getting the data is insufficient. We don't have great REAL-D (Race, Ethnicity, Language and Disability) and SOGI (Sexual Orientation and Gender Identity) data that the legislature is working on; there are all those things that are missing. But each layer that we peel back on why it is hard and why data collection systems are inefficient, helps give things to think about and questions to out into the community and ask how to remedy this. What criteria should the Public Health Division apply to remedy these actions. To Eli's point, are the staff trained, are the capable enough to engage in those conversations around data application and data collection with our community partners? I would say it is evolving and that is an important strategy and tactic to take where we are today and where we want to be tomorrow. We need to have a

relevant Public Health profession that help built trust and help get the data to that shared understanding.

Hongcheng- Whenever you have this challenge there is an opportunity and I can push a bit harder. Aggregate data, a huge challenge, is how you want to put it together but at the same time you lose information. If we want to push Public Health to actionable things down the road, we need to address this first. We need to start from there and that will improve community data by 50%.

Eli – notes that outside the academic world we don't use data for policy decisions, and this is a different situation. However, there are some groups, like the North Portland Area Indian Health Board, they have very specific regulations around what data is allowed to be released. They know who owns the data. We have had presentations in PHAB by different groups and my suggestion is to invite some of these groups to the PHAB and perhaps Rosemarie has some groups to suggest from the BIPOC communities. I think it would be useful to have a few of those groups to give us presentation on how they look at data and data collections. That would help us achieve that trust building that Rosemarie mentioned. That might give us more concrete suggestions on what avenue to take. It could be brief presentations.

Veronica – I agree with Eli's suggestions and wonder if there has been any needs assessment with some of the communities about data use, data collection strategies, and what they prefer. Is that something that has been done or are you intending to do?

Kirsten – It is at varying levels. Our Program Design and Evaluation Services which is between the state and Multnomah county have done some amazing work particularly with PSU and OHSU. Division of Equity and Inclusion has done fantastic work. Part of it is, there are programs that have a funding source that may generate a great conversation and how do we get spread for that.

Veronica – Also looking at other organizations within the state and who are their community partners. For example, transportation and see if they have community partner groups who are also using the public health data.

Diane – A question that came up from previous meetings and more colleagues at Public Health around how representative are organization and community leaders representing community members? Often community leaders are in positions of power and may not be representative of individuals and what would be the way to capture that?

Eli – you cannot reach every individual in society and that is why you have these representative groups. We need to essentially use those groups that we do have access and communication with and when you do a public hearing allow the entire community to react to it if they do not agree. I recall when the SHIP (State Health Improvement Plan) was developed, OHA was travelling around 10 or 15 different places in the state and they counted the number of people who were at each event. This include community representatives and individuals who had a chance to input into the planning of the SHIP. I think this model should be replicated. It is very time consuming and resource demanding, and I don't know if we have that at our disposal.

Hongcheng – also for the current list of stakeholders and users such as the public-school system.

Kirsten – they are also the collectors of data you need to have them agree to participate in the Student Wellness Survey and then they would say that that is their data because it belongs to the district. They are both end users and collectors.

Cara – At Thursday's full PHAB meeting, we are going to discuss public health survey modernization. Did we already talk about this opportunity to learn how to connect some of these dots around equity? If not, I will preface what this will be about.

For the last couple of years, the Public Health Division has funded communities to look at the data we have been collecting around our Behavioral Risk Factor Surveillance Survey which is a random digit dial survey for Oregon adults. For lots of reasons including the use of cell phones and portability area codes from state to state and from jurisdiction to jurisdiction, we have needed to look at different ways to administer the survey, how the questions are asked, who owns the data,

how the data are interpreted and shared and how the data is used for program policy and budget decision-making. We have funded the Coalition of Communities of Color and a Pacific Islander Modernization Project as well as the Northwest Portland Area Indian Health Board to focus on community-specific public health data collection. On Thursday, we will get an update on the work the community partner projects have been doing and then their recommendations for the future. This will be the grounding place on which to develop our Public Health Strategic Data Plan. It will address some of the questions in the Health Equity Review Policy and Procedures. I encourage Hongcheng and Dr. Hemmings to join us and we will have the meeting recording available. Slides are posted and hopefully at our next meeting we will be able to reflect and build from there.

Dr. Hemmings – Can you tell me how these specific organizations were selected?

Cara – At a high level, we were trying to pair researchers of color with organizations that would be able to pull community members into conversations about data priorities and be able to test and field some surveys. Through our work we were able to build on work that happened before our survey modernization with the Coalition of Communities of Color. They are supporting our Black African American and Latino, Latina and Latinx surveys. The Northwest Portland Area Indian Health Board also services as our Tribal Epidemiology Center and that was the best fit for our work with the Tribes. There is also the Tribal Behavioral Risk Factor Surveillance System Survey. Lastly, the Pacific Islander Data Project, they are contractors working to support that and some of the key partners were selected by members of the Data Team.

Dr. Hemmings – We just had this discussion about trust with the community and I'm trying to understand the connection and/or how close these organizations are to the actual community. Just because an organization has the title of BIPOC doesn't it mean and that actually closely connected or in line with the community as it relates to that trust factor.

Cara – I think I would like to get more information from the project team and will follow up via email.

Eli – will offer the PHAB package to Rosemarie. I was thinking about all the other surveillance programs, e.g. PRAMS. They all collect data one way or the other. We were wondering where to extract dental data from these surveys.

Diane – from the 2016 Data Inventory, there were 116 datasets. Some are no longer in existence and now there are some new ones in addition to the COVID data.

Eli – were we supposed to approve the charter?

Diane – I would say the answer is yes but based on the conversation that we have had today; I am wonder whether we need to modify the charter.

Public Comments and Questions

Martin Mendelson – Free Stake Person for the Multnomah County Democratic Party so my affiliation you will have to understand and is somewhat political. I am also a professor in the Department of Health Services in the School of Public Health at the University of Washington and have been teaching in medical schools for the last 60 years. I am also a graduate of the CDC Fellowship in Public Health Informatics. I would like to be put on your mailing list. I have emailed Kirsten to be added. I am delighted at what is going gone and the attributes you are addressing on why data is only the beginning. Need to pay attention at how data is combined, interpreted into something that allows us to act. Thank you!

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/subcommittee