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Testimony

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LC 45: Omnibus COVID-19 concept

Good Afternoon Chairs Courtney and Kotek and members of the committee, I am Patrick Allen, Oregon Health Authority Director.

I am here to testify about the importance of Race, Ethnicity, Language and Disability, known as “REAL D” data and recommend comprehensive collection of this data across the health system. Collecting this information is foundational to addressing health inequities. LC 45 requires REALD survey data collection by providers during an encounter with a patient for COVID-19 related health care – where currently this practice is not required, does not happen across health sectors and only happens with significant follow-up work by local county public health officials. OHA recommends that the legislature, agency, community partners and healthcare practitioners work together to extend the requirement beyond COVID-19 by 2021.

There is detrimental impact to not having this data now. We fail to serve Oregonians when we fail to collect this data. When we talk about dismantling institutionalized racism, a system that collects data for some individuals but not others is part of what needs dismantling. OHA’s goal is to eliminate all health disparities – while this bill is a step in the right direction, in the longer term we urge this legislature to expand the collection and reporting of REALD data for all health care encounters.

REALD data is a critical building block to reach Oregon Health Authority’s strategic goal to eliminate health inequities and rectify the root causes related to racism, discrimination and oppression. The Oregon Health Policy Board adopted the following definition for achieving health equity. OHA recognizes that health equity in our health system cannot be accomplished until all people can reach their full health potential and well-being and are not disadvantaged by their race, ethnicity, language, disability, gender, gender identity, sexual orientation, social class, intersections among these communities or identities, or other socially determined circumstances.

Achieving health equity requires the ongoing collaboration of all regions and sectors of the state, including tribal governments to address:

- The equitable distribution or redistribution of resources and power; and
- Recognizing, reconciling and rectifying historical and contemporary injustices.

Intention of HB 2134

In conjunction with community stakeholders, OHA and DHS worked to pass the REALD law in 2013, House Bill 2134, now codified as ORS 413.161. It was a critical step forward to our understanding of the disproportionate health impacts on Black/African American, Indigenous, and People of Color, people limited in English proficiency, and people with disabilities.

But the law has fallen short to meet the needs of our community. As we have seen time and again during COVID we do not have adequate data. Just looking at race data as an example, at the beginning of April, we had 36% of positive cases with unknown race. Since then, in partnership with Local Public Health Authorities, we have worked to improve race data collection through infectious disease investigations of positive cases, clinician case reporting, and work with clinical laboratories. As of June 17th, those with “unknown” race fell to 12.7%. However, we continue to not see race in testing overall – only positive cases, and there are more hurdles as we try to collect ethnicity, language and disability data.

The 2013 law requires OHA to establish standards for the collection of REALD data, and to collect REALD to the extent practicable, but the law does not require health care providers to collect REALD data from patients. OHA can ask or even require health care providers to submit data, but if the health care providers don't collect REALD compliant data from patients, the providers cannot report it to OHA.

OHA routinely collects demographic data from providers in order to promote population health – we estimate that we have at least 20 different datasets in OHA that relies on data collected from healthcare providers. All of these datasets are required to be in compliance with HB 2134, but have been unable to achieve that due to the challenges to requiring healthcare providers to comply with REALD.

It is difficult for OHA to meet the intention of the law and gather complete data sets without health practitioners participating in the collection of the data. In order to use the data as community intended, REALD standards need to extend beyond agencies and become the standard survey practice.

COVID-19

COVID-19 has put a clear spotlight on the importance of this data. Community leaders have asked repeatedly for OHA to complete the REALD data set so they can understand how this is impacting community.

Without this legislation OHA does not have the authority to standardize data collection by healthcare providers – we will continue to have missing and incomplete datasets that leave behind some of Oregon’s most impacted communities. Lack of REALD data collection standards from healthcare providers results in inconsistent and insufficient data collection. Consequently, we cannot adequately assess how race, disability and language access impacts individual and community health – particularly in times of a pandemic.

The point in which a person sees a health care provider is an important opportunity to collect REALD data. Health care providers should collect race, ethnicity, language, and disability data from their patients and if a patient requires a COVID-19 test, race and ethnicity information should be sent to the lab along with the testing order, so that information can be easily transmitted to OHA. Currently, health care providers collect race, ethnicity, language, and disability data in various ways and sometimes that information is incomplete.

OHA Recommendation

Through LC 45, We have brought forward our recommendations to require the collection of REALD data when a patient visits a practitioner.

OHA wants to work with practitioners and community partners to make REALD data available and actionable. OHA has submitted amendment language for your consideration that will help achieve this goal.

The proposed amendments would:

- Only require the collection of REALD data at the time a health care practitioner is ordering a COVID-19 test for a patient.
- Require OHA to adopt rules to prevent duplicate collection of REALD data from multiple providers.
- Require the collection of the data to begin no later than Oct 1, 2020, but in phases and not all at once.
- Require OHA to provide a template to health care providers for collecting the data
- Explicitly state the data is subject to federal and state privacy laws

With REALD data, together we can: use information to improve access to testing and medical treatment; design culturally appropriate and accessible interventions to

improve testing, prevention and treatment; and reallocate resources and power needed to effectively address these inequities. Comprehensive REALD collection will allow us to unmask inequities and institutional structures that propel inequities.