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## LC 440: REALD & SOGI Confidentiality

Protecting people's information, especially for marginalized communities, should be a right.

### **Race, Ethnicity, Language & Disability and Sexual Orientation & Gender Data**

Race, ethnicity, language & disability (REALD) and sexual orientation & gender identity (SOGI) information is vital to identifying and address social and health inequities. With it, state programs and community-driven efforts can focus on the specific needs of groups experiencing particular health concerns. Without it, there is simply no way to identify health inequities, as health concerns of minority populations literally get overlooked within the larger accumulation of more generalized data.

### **REALD and SOGI Data is Currently Not Confidential**

Currently REALD & SOGI information is a public record under Oregon state law (ORS 192.311 to 192.478). As such, it is subject to the Public Records Act, which generally makes records available to the public upon request unless there is a specific exemption allowing them to be kept confidential.

Unfortunately, sharing and or reporting individual's responses to REALD & SOGI questions in response to a public records request:

- ▶ Increases the possibility of harm and exposure to racism, disablism, linguistic discrimination, transphobia, homophobia and heterosexism. When combined with other identifiers, it can enable bad actors to prey on those most vulnerable
- ▶ Reduces quality of REALD & SOGI data, which in turn make it harder for OHA & ODHS to identify and address inequities in services, outcomes and in processes, ensure language access and ADA accessibility, and ensure diverse representation on committees, workgroups, rulemaking advisory committees, workforce (internal and external), and in other settings with external community members
- ▶ Reduces OHA and ODHS's ability to implementing REALD & SOGI well which in turn reduces ability of communities most impacted to do data justice.

When OHA and ODHS collect REALD & SOGI data, the agencies must be transparent with respondents about their limited ability to protect this information in cases, as it is not confidential. This leads to lower response rate, which makes the information limited in usefulness if there are low response rates.

### **Protecting REALD and SOGI Data Confidentiality**

LC 440 establishes that REALD and SOGI information collected by OHA and ODHS (under ORS 413.161) is subject to the confidentiality clause related to collection and reporting of data by health care providers and insurers (in ORS 413.164(4)). This makes the data not subject to disclosure under the Public Records Act.

This still allows the data to be released in anonymized and aggregated form, so long as it does not reasonably allow an individual whose information is included in the data to be identified. Therefore, the data, like other health data from health care providers and insurers, will be available for broader reports on public health.

LC 440 also exempts REALD and SOGI questions from ORS 181A.823, which restricts state agencies from asking about a person's immigration status except for particular purposes. This restriction is relevant to the first standard REALD race/ethnicity question: "How do you identify your race, ethnicity, tribal affiliation, country of origin, or ancestry?"

This data is not sought for the purpose of collecting information about immigration status, nor is it shared with federal immigration authorities. OHA & ODHS consider REALD information to be demographic in nature, and state rules specify that demographic data cannot affect eligibility or inclusion in any program or benefit. The statutory change would mean OHA and ODHS could continue to collect REALD information for demographic and public health purposes.

**For more information:**

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