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February 13, 2023

Senator Deb Patterson, Chair
Senator Cedric Hayden, Vice-Chair
Senate Committee on Health Care
900 Court Street NE
State Capitol
Salem, OR 97301

Dear Chair Patterson, Vice-Chair Hayden, and Committee Members:

Please find below answers to several questions raised during the February 8, 2023, work session on SB 216, regarding REALD/SOGI data.

Why is individual level data important to OHA?

Individual level data provides flexibility for OHA to effectively perform its functions – for example, for Oregon Health Plan (OHP) enrollment, medical claims and payments, as well as for birth and death records purposes. Accordingly, OHA collects, stores, analyzes, and shares individual level data as permitted by law.

Additionally, collection and analysis of individual level data allows OHA to better control for statistical bias, thus leading to more accurate and precise analysis of population-level health outcomes and causes of health disparities.

When does OHA share individual level data?

OHA shares individual data back with programs that serve OHP clients, such as Coordinated Care Organizations or other health service providers, consistent with the privacy protections in the federal Health Insurance Portability and Accountability Act and other state and federal laws.

There might also be a need to share more specific data – other than aggregate and anonymized data – with local public health authorities (LPHAs) for the purposes of improving health equity metrics. OHA can share individualized data only when authorized by law.

Why is it being proposed to eliminate language limiting disclosures to the anonymization and aggregation of data?

ORS 413.163 (House Bill 3159 (2021)) requires OHA to:

“...Establish a data system for data on race, ethnicity, preferred spoken and written languages, disability status, sexual orientation and gender identity collected under ORS 413.164. The data system established under this section must include:

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1. *A data registry to receive and store the data described in this section from coordinated care organizations, health care providers and health insurers, patients, clients and members of coordinated care organizations, health care providers and health insurers, the authority and the Department of Human Services. The registry must allow for coordinated care organizations, health care providers and health insurers to:
 - a. *Electronically submit data collected under ORS 413.164; and*
 - b. *Query the data registry to determine whether the registry contains current data for a patient, member or client.**
2. *Functionality that allows a patient, member or client to directly submit to the data system their data described in this section.”*

OHA will be receiving individualized data through the system established above. However, the current language in ORS 413.164(4) prevents release of data unless aggregated and anonymized. This language protects race, ethnicity, ancestry, language or disability (REALD) and sexual orientation and gender identity (SOGI) data but could be read to limit the current lawful ways in which OHA can share identifiable data, thus significantly affecting the functioning of OHP and other health-related programs. Even with this change in ORS 413.164(4), OHA still could share individualized data only when authorized by law.

Would elimination of this requirement impact only new data collected, or retroactively impact providers?

The language in current statute, ORS 413.164(4) only would apply to data collected once the registry is established and OHA had adopted rules for collection and reporting.

Please do not hesitate to reach out if you have any further questions or clarifications.

Sincerely,



James M. Schroeder
Interim Director