

Date: May 22, 2024

To: Oregon Health Authority REALD-SOGI Rules Advisory Committee

From: Betsy Boyd-Flynn, Executive Director & CEO, on behalf of the Oregon Academy of Family Physicians

Subject: Notice of Proposed Rulemaking: SOGI Updates to REALD Demographic Data Collection and Reporting

The Oregon Academy of Family Physicians (OAFP) is an organization of more than 1700 members, including medical students, residents in training, and practicing physicians in almost every care setting. We take seriously our responsibility to protect and honor the special, trusting relationship patients have with us as clinicians. We are committed to “whole person” health care that takes into consideration all the factors that can impact a patient’s health, healing, and wellbeing. As clinicians, we respect our patients’ autonomy and their right to disclose, or not disclose, whatever information they may wish to share with us. That said, we are in full support of the state's intent stated in the Notice of Proposed Rulemaking to “standardiz[e] REALD & SOGI data collection [so that] OHA and ODHS can better identify and address social and health inequities,” which is a goal we share.

The Oregon Health Authority’s work pursuant to HB 3159 to design and implement a comprehensive data collection process for sexual orientation and gender identity (SOGI) data in health care and social service contexts is an important part of the fight for equity for all Oregonians. We are grateful for the opportunity to offer comments on this process.

Our comments are detailed below, but can be summarized as follows:

1. Consider unintended impact on vulnerable Oregonians and use clear language
2. Clarify timing of collection and intended use to ensure privacy
3. Thoroughly consideration the economic impact of implementation
4. Consider patient experience across the health and social support system

1. Consider unintended impact on vulnerable Oregonians and use clear language

We understand the intent to ask these questions in a clinical setting as a public health intervention to create an atmosphere of safety for vulnerable individuals from the LGBTQI2S+ community, and agree that youth benefit from an atmosphere where they feel seen and welcomed. However, we echo the concerns of the Oregon Pediatric Society and Children’s Health Alliance related to the implementation of these rules for pediatric and adolescent Oregonians. We agree with their comments that emphasize the need to match patient age with developmentally appropriate language and concepts in the questions themselves. We share their concern over the real risk posed to youth and adolescents under age 18 if this data is collected and stored in their medical records, especially given that the health records for patients younger than fourteen cannot be legally kept confidential from parents and caregivers.

It is unlikely that surveys about sexual orientation and gender identity completed by parents, or in the presence of parents or caregivers, will yield reliable data for purposes of addressing health inequities. Implementing a process of this kind for a broad patient population should only be done if the benefit of having the resulting data outweighs the potential harms. While it is laudable to want clinical and social-service spaces to be made to be more welcoming to vulnerable patients, we are concerned that the risks to vulnerable youth outweigh the benefit.

Recommendation: Regarding the language in the survey questions, we believe section 950-030-0020 (3)(c), which states “Questions must be asked in the exact way they are worded in these rules, except that pronouns can be changed or substituted with proper nouns” must not be implemented at this time until the questions can be assessed with respect to health literacy or age and developmental appropriateness. If individuals cannot understand the questions being asked, and if requestors may not use any other language than what is in rule, data completeness and accuracy will suffer.

2. Clarify timing of collection and intended use to ensure privacy

Recommendation: Clarify timing of data collection. Section 1(2) of the statute states that data must be collected “at least once each calendar year” but the rules refer to a rolling twelve-month collection. This is a material difference given that data collection is expected to impact more than twenty types of providers a patient may encounter each year. When a provider checks a database, seeing whether the date is within the calendar year vs. the last 12 months is much faster.

Recommendation: Clarify whether the data collected through these questions shall be treated as demographic or clinical. The proposed rules refer to the data as demographic throughout, but guidance language recommends telling individuals “We ask everyone about their demographic information so that we can ensure that everyone receives the highest quality of care and services.”¹ This implies that the data will be used to inform *that individual’s* care. This makes sense in that clinicians should limit their inquiries of their patients to information that is relevant to their care. However, we believe that means that the data is *inherently clinical in nature, and not demographic*. Patients may have different levels of comfort disclosing data to be used to inform their clinical care versus data to be reported to the state for demographic purposes.

In addition, we urge the state to carefully consider whether it is appropriate for clinicians to share individually identifiable data with the OHA for these purposes. Because the intent is to use these granular data elements to report on equity for patient populations that might be quite small, this may pose a risk to patients in those small groups. Clarification throughout the rules would inform patient control over their data, and better explain clinician responsibility over data transmission and storage.

Recommendation: Clarify that the state will protect the data.

¹ <https://www.oregon.gov/oha/EI/Documents/GuidancetoAccompanyChangestoOARs.pdf>

In the “Statement Identifying how Adoption of Rule(s) Will Affect Racial Equity in This State” there is no mention made of how granular data reporting will be, and the rules do not explicitly identify which data sets this data will be combined with. Best practices in handling confidential data used for statistical reporting include taking steps to ensure that the privacy of the individuals in the sample size is not at risk of exposure². To align with the statute language Section 1(3)(b)(C)(iv)(4) that states “Data collected under this section is confidential and not subject to disclosure under ORS 192.311 to 192.478. The authority may release the data collected under this section only if the data to be released is anonymized and aggregated so that the data released does not reasonably allow an individual whose information is included in the data to be identified,” the rules must clearly identify what steps the OHA will take to ensure that any publicly reported information based on SOGI data cannot expose the individuals in those samples to public identification.

3. Thoroughly consideration the economic impact of implementation

Though the notice of the final rulemaking references some consideration of economic impact, we expect that more comprehensive analysis will be conducted during later stages of implementation. That said, new data collection will create an administrative burden on clinics, and a financial burden. The structure of these questions and the method used to collect the information cannot be separated from that economic impact.

While assessing the cost is outside the scope of the current Rules Advisory Committee and rulemaking, the technology acquisition and associated costs bear consideration for the rules implementation timeline and technical support to entities.

Recommendation: Seek more detailed information from more small-business and community-based organizations. The statute and rules indicate that Community Based Organizations (CBOs) will required to collect and report this data, but these entities often do not utilize Electronic Health Records systems, and will require guidance on collecting data in a HIPAA compliant manner.

Include a timeline, in rule or guidance, for providers to acquire or upgrade Electronic Health Records or other client data systems capable of collecting this data interoperably, so that the fields are common across all settings.

4. Consider patient experience across the health and social support system

Recommendation: Consider rules that will allow for practical or common-sense flexibility.

² “Protecting privacy when disclosing statistics based on small samples” Centre for Economic Policy Research <https://cepr.org/voxeu/columns/protecting-privacy-when-disclosing-statistics-based-small-samples>

As stated in the guidance document, the intent of the statute and rulemaking process is “to require REALD & SOGI data collection regardless of current technical or other business restraints.”³ Understanding that this intent is reflective of the state’s urgency on this issue, we ask that the rules be considered with clearer understanding of the resultant patient experience. Will every provider a patient sees present these questions to be answered annually? We envision a circumstance where a patient who visits a PCP annually, who also visits an urgent care, who also sees an optometrist and a dermatologist and visits a food bank in a given calendar year will be asked these questions once by each provider, even if they have declined to answer the questions in a different provider’s presence. Additionally, the rules do not address the possibility that a patient presenting in acute pain or in an unconscious state might not be able to answer the questions as part of intake.

Recommendation: Make individuals opting-out or controlling their data straightforward. The survey instrument must have an option for patients who wish to disclose the data to a requesting provider for purposes of receiving services *in that setting* but who may not wish to share the information with other providers. For example, while a patient might feel comfortable sharing this information with their PCP, it might not be relevant for their care from an optometrist or from a pharmacy technician who administers a vaccine. Put another way, the rules must allow patients to control disclosure of this data separately from their other clinical data, to protect the trust between patient and provider. We recommend the addition of an additional question to the effect of “May we share this data to other health care providers with the rest of your health record?”

Recommendation: Clarify all modalities for collecting the data. Draft rules refer to “requestor” as though the questions must be asked verbally. Section 950-030-0020 (4) reads “Before collecting REALD and SOGI information, *the person* filling out...” [emphasis added] This indicates that an individual will verbally ask these questions of the individual receiving services. Yet (13) refers to “Entities using online platforms to collect REALD and SOGI information,” indicating that this modality is permissible. The rules must clearly indicate that organizations have the flexibility to construct workflows to collect the data in the way that best fits their service delivery team. The rules must clarify that providing a patient with a paper survey form similar to a PHQ-9, or including the questions as part of online pre-appointment registration are also acceptable modalities for collecting the data.

In Section 2(2), the statute further states that the system must include “Functionality that allows a patient, member or client to directly submit to the data system their data described in this section” but the rules are written as though the data will always be collected by a “requestor.”

Recommendation: Clarify when it is not necessary to collect the data

Draft rule 950-030-0020 (12) is unclear and contradictory, and not responsive to individuals who decline to answer the questions. In Section 2(1)(b) the statute provides that the registry must allow health care

³ <https://www.oregon.gov/oha/EI/Documents/GuidancetoAccompanyChangestoOARs.pdf>

providers and health insurers to “Query the data registry to determine whether the registry contains current data for a patient, member or client.” If the provider can determine that the data is current (for example because it was collected by another provider the prior week) the provider should not have to ask the questions again. The rules should reflect this.

We understand this work is sensitive and urgent, and we stand ready to help source the additional information we recommend that OHA seek. Having sound and implementable administrative rules, and associated guidance, necessitates a more thorough review right now before being brought forward for adoption. Ensuring we are honoring the spirit of the legislation while we adhere to best practices in patient experience must remain central to the development of this work.

Respectfully,

Betsy Boyd-Flynn
Executive Director & CEO, Oregon AFP
bbf@oafp.org