Guidance for data collection implementation to accompany the proposed OARs updates (May 2024)

Oregon Health Authority Equity & Inclusion Division, REALD & SOGI Section

Overview

This document provides guidance on **how** to implement the REALD & SOGI requirements being proposed (950-030-0000 through 950-030-0200). The catalyst for these updates is House Bill 3159 (2021) (ORS 413.163), which required Sexual Orientation and Gender Identity (SOGI) to be added to the existing REALD (Race, Ethnicity, Language and Disability) data collection standards, which also needed updating. It is not intended to provide an in-depth breakdown of all the questions and categories, but instead addresses pieces where we have heard the most questions or confusion.

This guidance includes the following topics:

Who are required to implement these changes once they are finalized?

To the greatest extent practicable, all programs and activities of Oregon Health Authority, including contractors and subcontractors, must collect REALD (and SOGI once finalized July 2024) demographic data. The intent is to require REALD & SOGI data collection regardless of current technical or other business restraints. While not explicit in the proposed OARs, Oregon Department of Human Services and their contractors are also expected to conform with these OARs.

CCOs and Insurers Reporting to OHA All Payers All Claims (APAC):

Insurers with 5000+ members in Oregon will be required to submit REALD & SOGI to OHA All Payers All Claims (APAC; ORS 442.373(2)(b)(C)) in January 2025.

Licensed providers and other insurers not reporting to APAC in Oregon.

Per ORS 413.164 (HB 3159), licensed providers and remaining insurers not reporting to APAC will be required to submit REALD & SOGI to OHA once OHA has built a data system to receive data from CCOs, providers and insurers, **we anticipate that this system will go live late 2026 or early 2027**. Providers who are currently sharing data with OHA are encouraged to update to the new 2024 standards; CSV updated specifications and instructions will be shared later this summer/fall.

REALD & SOGI Form Instructions

It is critical to provide messaging such as the following:

*We would like you to share your demographic information so that we can find and address health and service differences. We ask **everyone** about their demographic information so that we can ensure that **everyone** receives the highest quality of care and services. These questions are optional (with an option select "don't want to answer" or "don't know"). Your answers are confidential but will be used by OHA to identify and address inequities and improve services.*

Questions about who is providing / answering the questions

The proposed REALD & SOGI OARs start with two questions:

A1a. Who is filling out this form?* Select one:

☐ The individual alone   ☐ Another person with the individual present

☐ The individual with another person present   ☐ Another person without the individual present

A1b. Who was present with the individual when the data was reported? Select one:

☐ A parent/guardian   ☐ An interpreter or other professional support(s)

☐ Another family member   ☐ Not listed, please specify: _____

                                ☐ N/A, the individual or another person is filling this out alone

A2. What is your date of birth (MM/DD/YYYY)? _____

These questions apply to the person filling out the form. For example, the individual being asked to fill this out, the person filling this out in a phone interview or in-person intake. If it is not clear if there is another person present during a phone interview, then ask. See below for some scenarios.

Scenario A: head of household answers for everyone

Some systems have one person per household answer questions for everyone in the household. In this case, the two questions about who is providing the data can be answered by the system, and neither question would be visible to the individual filling out the form. The system would automatically answer questions A1a and A1b based on who the questions are about. For questions about household members other than the individual answering the questions, the system would mark **"Another person without the individual present"** for question A1a. For questions about children, the system would mark "***A parent/guardian***" for A1b, and for questions about other household members, the system would mark "***another family member***".

Scenario B: in person or phone interview

If REALD & SOGI are being collected via in person or phone interviews, the interviewer should mark down whether the question is being answered by the individual or by someone else in question A1a. If it is not clear whether another

person is present, the interviewer would ask question A1b, **"*Who is present with the individual [during this interview]*?"**.

Scenario C: parent and child handed form while waiting for appointment

If REALD & SOGI are collected via a paper form that is filled out prior to or during an appointment, questions A1a and A1b should appear at the top of the form. Alternatively, if a receptionist or other staff member can observe who is answering the questions and who is present with them, that staff member may fill in the answers to questions A1a and A1b.

Open-ended questions

OARs require the use of an open-ended question to elicit an unprompted response.

Having an option to answer an open-ended question is important to people who do not like labels or have other identities outside of categories. The open-ended question provides a way to honor that and helps with data quality, before getting into categories. OHA, REALD and SOGI section, has been utilizing tools such as tableau prep to fully maximize the use of open text responses and is happy to share how we do that.

Additional answer option: "Don't know what this question is asking"

Most questions asked include a "**Don't know**" or "**Don't want to answer**" option: open ended questions are excluded from this requirement. Two disability (questions 13 and 15) and three SOGI (questions 19, 20, and 23) questions include the answer option "**Don't know what this question is asking**".

Age-based skip logic

Many of the REALD and SOGI questions have skip logic based on the age of the individual answering the questions. In order to reduce survey fatigue, it is important to use both skip logic and display logic in an electronic format and clearly indicate on paper forms the skip patterns. Below is a list of age-based skip logic in the REALD and SOGI OARs.

Language

- If the individual is under age 5, skip all language questions (questions 4-6).

Disability

- If the individual is under age 5, ask questions 7 and 8, then skip all remaining disability questions (questions 9-17).
- If the individual is between the ages 5 and 15, ask questions 7-13, skip questions 13 and 15, then ask questions 16 and 17.

Gender identity

- If the individual is between age 5 and 12, skip the adult gender identity questions (questions 18-20) and ask question 24.
  - In this case, the question "what is your sex" (question 21) should still be asked, but asked *after* the gender identity question.

Sexual orientation

- If the individual is under age 12, skip all sexual orientation questions (questions 22 and 23)

Race and ethnicity

See the overview of what changed in terms of the race and ethnicity categories in 2024. Additional race and ethnicity categories have been added to the REALD survey based on feedback from the RAC and the need to align with the proposed Federal revisions to race and ethnicity released in March 2024. Our intent is to both honor the requests from the RAC process and facilitate everyone's compliance with the new OMB changes. See the cross-maps to see how the 2024 Race and Ethnicity categories will map to the 2020 standards, as well as the OMB standards.

Many of the Federal revisions to race and ethnicity were already aligned with REALD. Through the RAC process, 20 granular race and ethnicity categories and 1 parent category were added to be more responsive and inclusive as to how Oregon community members identify themselves. Alignment with proposed Federal revisions to race and ethnicity categories resulted in the addition of 16 race and ethnicity categories as well as open text questions where respondents can add more detail.

It is important to display the questions as shown in the template, for example, electronically or paper form. However, if this is done by phone, one should use a phone script where responses to the aggregate categories lead to disaggregate categories (will plan to update the phone script in the Fall of 2024). If detailed race and ethnicity data are collected in an interviewer-administered setting (such as phone or in person), the minimum categories should be asked first, followed by the detailed categories associated with the selected minimum categories.

The mode of data collection may offer additional options for collecting detailed data. In electronic modes of collection, for example, agencies may use multiple screens to collect detailed data. The minimum reporting categories may be collected on an initial screen and detailed data for each minimum reporting category the respondent selected may be collected on follow up screens, whether through checkboxes, drop down menus, write-in areas, or another method.

Primary racial or ethnic identity

Question 3 under Race and Ethnicity asks: "**If you checked more than one category, is there one you think of as your primary racial or ethnic identity?**" When collecting REALD & SOGI on paper, the option "Yes. Please circle your primary racial or ethnic identity above" is appropriate. When collecting REALD & SOGI electronically, if someone answers "yes" to this question, they should be presented the list of racial or ethnic identities they indicated in question 2 and be asked to select the one they think of as their primary identity.

Language

Language Lists for Home language, Spoken Language, Written Language. As noted by 950-030-0040 (5) Entities collecting language data using ISO 638 standards must use the full ISO code list provided by OHA that includes local codes as well.

This list of over 7,000 languages works best with the use of smart filtering where as one begins to type the name of the language, the pertinent language(s) will show up for the person to select. The REALD and SOGI team at OHA is happy to provide technical assistance and guidance on how to implement the full ISO code list.

Triage Language Question. We add a new question 4a: **Do you only use English at home**? to serve as a triage question. If the answer is yes, the respondent may skip to the next section; if the answer is no, there are further language questions to answer.

Interpreter Type Question. Question 5b "**If you need or want an interpreter or language access, what type of interpreter or language access is preferred? Select ALL that apply.** "This has been updated to add additional options:

- ❑ Spoken language interpreter
- ❑ Assistive Listening Device (FM, Loop) (please specify)
- ❑ CART/Captioning
  Sign Language
  - ❑ American Sign Language interpreter
  - ❑ Mexican Sign Language interpreter
  - ❑ Tactile/Protactile Sign Language
  - ❑ Certified Deaf Interpreter for DeafBlind, additional barriers, or both
  - ❑ Contact sign language (PSE) interpreter
  - ❑ Another sign language not listed (please specify)

Gender identity

Culturally or ethnically specific gender identities.

The terms people use to describe their gender identity, as well as the way they conceptualize gender and those identities, vary from one culture to another. Some examples of culturally or ethnically specific identities that differ from Western concepts of gender include "Two-Spirit" in

American Indian and Alaskan Native (AI/AN) contexts and "Māhū" in Native Hawaii'an contexts. To avoid appropriation of culturally specific terms, it is recommended not to list the culturally specific terms, such as "Two-Spirit".

When collecting REALD and SOGI data electronically, it is recommended to ask the Race and Ethnicity questions first so that people see additional gender identity categories based on their answer to the race/ethnicity questions. For example, someone who identifies as one or more Pacific Islander races/ethnicities may see the options "Māhū" and "Fa'afafine" alongside the other gender identity categories. We recognize that this is not always possible; questions may be asked in person, over the phone, or on paper, or a system may not be able to collect REALD prior to collecting SOGI. The option "*I have a gender identity not listed here that is specific to my ethnicity*: _____" is appropriate for scenarios where the SOGI categories presented cannot be linked to REALD data.

Sex

REALD & SOGI includes *one required question* about sex (21). This question allows requestors to capture accurate information about individuals' current sex. This question is particularly important for allowing data analysts to represent intersex experiences.

21. What is your sex?
☐ Female   ☐ Intersex   ☐ Don't want to answer
☐ Male   ☐ Don't know   ☐ Not listed, my sex is: _____

The question "**What is your sex**" is preferred over "when you were born, what sex was assigned to you" or "what is the sex listed on your birth certificate", for two reasons. First, because people's bodies change for a variety of reasons, sex assigned at birth does not provide accurate information about a person's body. Second, many intersex people were not assigned intersex at birth or do not have intersex listed on all relevant documentation.

Some requestors may have additional reporting or verification requirements that are not met by responses to 21. For example, a benefits eligibility system may require the sex designation that matches a person's record with the Social Security Administration. **The following questions are <u>not required</u> but are recommended best practices to meet these reporting or verification requirements.** Requestors should include language indicating how this information will be used and/or why it is required.

> 21b. Is your current sex different from the sex listed on your [specific document/s]?
> ☐ Yes ☐ No
>   If yes, please list the sex that matches your [specific document/s]: _____

Requestors are recommended to ask only for the specific information needed to meet requirements. Some examples of documents that requestors may want to ask can include:

- Birth certificate
- State or tribal ID (such as driver's license)
- Health insurance record
- Current or previous medical documents
- Federal ID (such as social security)
- Sex assigned at birth

Scenario A: Benefits eligibility application

Needs:

- Current sex for accurate representation
- Sex on federal documents for identity verification and reporting
- Sex assigned at birth for reporting

Required:

21a. What is your sex?		
☐ Female	☐ Intersex	☐ Don't want to answer
☐ Male	☐ Don't know	☐ Not listed, my sex is: _____

Recommended to capture additional needs:

21b. Is your current sex different from the sex listed on your federal ID (such as social security card)? ☐ Yes ☐ No

    If yes, please list the sex that matches your:

    Sex assigned at birth: _____

    Federal ID: _____

Skip logic applies, displaying follow-up only if responder selects 'yes'.

Scenario B: Healthcare clinic

Needs:

- Current sex for accurate representation
- Sex on health insurance records for billing
- Sex on past medical records for records sharing requests
- Sex on federal documents for reporting
- Binary sex assigned at birth for reporting

Required:

21a. What is your sex?
☐ Female   ☐ Intersex   ☐ Don't want to <u>answer</u>
☐ Male   ☐ Don't know   ☐ Not listed, my sex is: _____

Recommended to capture additional needs:

21b. Is your current sex different from your sex assigned at birth or the sex listed on your federal ID (e.g., social security card), health insurance records, or current/previous medical documents? ☐ Yes ☐ No
     If yes, please list the sex that matches your:
     Sex assigned at birth: _____
     Federal ID: _____
     Health insurance records: _____
     Current or previous medical documents: _____

Skip logic applies, displaying follow-up only if responder selects 'yes'.

Scenario C: Health-related survey

Needs:

- Current sex for accurate representation

Required:

21. What is your sex?
☐ Female   ☐ Intersex   ☐ Don't want to answer
☐ Male   ☐ Don't know   ☐ Not listed, my sex is: _____