



REALD & SOGI and APAC

Equity & Inclusion Division

Three Major Areas to Cover

- The history and context of REALD & SOGI
- Data standards and reporting requirements
- Background to the REALD & SOGI Initial Repository & Initial Registry

OHA Strategic Goal to eliminate health inequities by 2030

REALD & SOGI categories are proxies of exposure to racism and other systems of oppression

We must commit to developing systems to collect and use REALD & SOGI data to make data informed decisions instead of data driven decisions

Collecting REALD & SOGI is a manifestation of data justice - REALD & SOGI came from communities. We must do data equity so that communities can do data justice (elevate voices and reveal systemic inequities)

What gets counted, counts!

- **“Complete and accurate data are essential** for tracking how health outcomes and access to high-quality care differ for different racial and ethnic groups and how such differences vary geographically and over time” (Urban Institute, Haley, et al., 2022).
- **...lack of adequately disaggregated data** impacts communities by making “them invisible when policies are made, resources are allocated, and programs are designed and implemented” (Hasnain-Wynia, et al 2012)



How REALD data collection standards were developed

2013/2014

- Formal rulemaking advisory committee (RAC) developed the standards. The following factors considered for inclusion in the rules were:
 - Local populations in Oregon
 - An existing data collection tool developed by the Coalition of Communities of Color
 - Populational level questions (not disease specific for example)
 - National standards for comparability – particularly for disability and English proficiency

2020

- Added 5 new r/e categories based on Covid impact as well as state population figures
- 3 new disability questions
- Revised language questions
- Clarified OARs to indicate contractors and subcontractors' obligations

2023/24

- HB 3159 RAC in progress
- Adopt SOGI questions and expand REALD categories

Why consistent data standards?

“The goal of eliminating disparities in health care in the United States **remains elusive...**”

- (Ulmer et al., 2009, p. 1; Institute of Medicine)

The lack of granularity in race/ethnicity can “...**mask important inequities in health and health care.**” (Ulmer et al., 2009, p. 31)

- With consistent demographic data, together we can:
 - Improve client/patient/member services and reduce inequities
 - Identify inequities; determine what groups are most impacted
 - **Reduce health care costs by addressing inequities and disparities**
 - Address identified inequities through policy and legislative efforts
 - Reallocate resources needed to address inequities
 - Design culturally appropriate and accessible interventions

What are the laws governing REALD & SOGI?

- **HB 2134 (2013) - ORS 413.161:** Requires OHA & ODHS to collect/store REALD (race, ethnicity, language & disability) data in all datasets with any type of demographics
- **HB 4212 (2020):** Requires providers to collect and report REALD for Covid-19 encounters
- Neither **HB 2134** nor **HB 4212** included **SOGI** (sexual orientation & gender identity)
- **HB 3159 (2021):** Adds SOGI, Requires REALD and SOGI collection on all patients from providers & insurers. **HB 3159 does not** replace HB 2134

HB 3159 Data Justice Act

- Amended **ORS 413.161** to include SOGI
- Requires providers/insurers/CCOs to submit REALD & SOGI data annually
- Providers/Insurers must inform patients that:
 - REALD & SOGI data is reported to OHA
 - How the data may and may not be used
 - That they are not required to answer (can decline)
- Registry must allow individuals to directly update their REALD & SOGI information

REALD & SOGI Questions & Categories

Core principles – Self-report

“When an individual self-identifies as being from a certain population subgroup, it may also mean that the individual is more likely to have health beliefs, health care use patterns, and perspectives about the health care system that are common to that community.”

(Hasnain-Wynia & Baker, 2006, p. 1509)

Perceptions vs Self-Report – Ex.
Most patients with disabilities “... were not perceived by their clinicians and clinic staff members to have physical limitations that potentially would impede cancer screening”

(Buckley et al., 2012, p. 1349).

Race and Ethnicity

1. How do you identify your race, ethnicity, tribal affiliation, country of origin, or ancestry?

2. Which of the following describes your racial or ethnic identity? Please check **ALL** that apply.

Hispanic and Latino/a/x

- Central American
- Mexican
- South American
- Other Hispanic or Latino/a/x

Native Hawaiian and Pacific Islander

- Chamoru (Chamorro)
- Marshallese
- Communities of the Micronesian Region
- Native Hawaiian
- Samoan
- Other Pacific Islander

White

- Eastern European
- Slavic
- Western European
- Other White

American Indian and Alaska Native

- American Indian
- Alaska Native
- Canadian Inuit, Metis, or First Nation
- Indigenous Mexican, Central American, or South American

Black and African American

- African American
- Afro-Caribbean
- Ethiopian
- Somali
- Other African (Black)
- Other Black

Middle Eastern/North African

- Middle Eastern
- North African

Asian

- Asian Indian
- Cambodian
- Chinese
- Communities of Myanmar
- Filipino/a
- Hmong
- Japanese
- Korean
- Laotian
- South Asian
- Vietnamese
- Other Asian

Other Categories

- Other (please list)
- Don't know
- Don't want to answer

3. If you checked **more than one** category above, is there **one** you think of as your **primary** racial or ethnic identity?

- Yes. Please circle your primary racial or ethnic identity above.
- I do not have just one primary racial or ethnic identity.
- No. I identify as Biracial or Multiracial.
- N/A. I only checked one category above.
- Don't know
- Don't want to answer

Open-ended question

39 racial/ethnic identity options

If more than one selected

Primary race question

Language questions – client/service/patient base settings

Language (*Interpreters are available at no charge*)

4a. What language or languages do you **use at home**? _____

Skip to question 7 if you indicated English only

4b. In what language do you want us to communicate in **person, on the phone, or virtually** with you?

4c. In what language do you want us to **write** to you? _____

5a. Do you need or want an **interpreter** for us to communicate with you?

Yes No Don't know Don't want to answer

5b. If you need or want an interpreter, what type of interpreter is preferred?

- | | |
|--|---|
| <input type="checkbox"/> Spoken language interpreter | <input type="checkbox"/> Deaf Interpreter for DeafBlind, additional barriers, or both |
| <input type="checkbox"/> American Sign Language interpreter | <input type="checkbox"/> Contact sign language (PSE) interpreter |
| <input type="checkbox"/> Other (<i>please list</i>): _____ | |

Skip to question 7 if you do not use a language other than English or sign language

6. How well do you speak English?

Very Well Well Not Well Not at all Don't know Don't want to answer

Disability questions

Questions are not identity-based; helps count people with disabilities most likely to experience disablism

There is a follow-up question if a person answers yes:

“At what age did this condition begin?”

Your answers will help us find health and service differences among people with and without functional difficulties. Your answers are confidential.

7. Are you **deaf** or do you have **serious difficulty hearing**?

- Yes Don't know
 No Don't want to answer

If **yes**, at what age did this condition begin? ____

8. Are you **blind** or do you have **serious difficulty seeing**, even when wearing glasses?

- Yes Don't know
 No Don't want to answer

If **yes**, at what age did this condition begin? ____

Please stop now if you/the person is under age 5

9. Do you have serious difficulty **walking or climbing stairs**?

- Yes Don't know
 No Don't want to answer

If **yes**, at what age did this condition begin? ____

10. Because of a physical, mental or emotional condition, do you have serious difficulty **concentrating, remembering or making decisions**?

- Yes Don't know
 No Don't want to answer

11. Do you have **difficulty dressing or bathing**?

- Yes Don't know
 No Don't want to answer

If **yes**, at what age did this condition begin? ____

12. Do you have serious difficulty learning how to do things most people your age can learn?

- Yes Don't know
 No Don't want to answer

If **yes**, at what age did this condition begin? ____

13. Using your **usual (customary) language**, do you have **serious difficulty communicating**, (*for example understanding or being understood by others*)

- Yes Don't want to answer
 No I don't know what this question is asking
 Don't know

If **yes**, at what age did this condition begin? ____

Please stop now if you/the person is under age 15

14. Because of a **physical, mental or emotional condition**, do you have difficulty doing **errands alone** such as visiting a doctor's office or shopping?

- Yes Don't know
 No Don't want to answer

If **yes**, at what age did this condition begin? ____

15. Do you have serious difficulty with the following: mood, intense feelings, controlling your behavior, or experiencing delusions or hallucinations?

- Yes Don't want to answer
 No I don't know what this question is asking
 Don't know

If **yes**, at what age did this condition begin? ____

SOGI Questions

1. Please describe your gender in any way you prefer:

2. What is your gender? (check all that apply)

- Girl, Woman Boy, Man Non-binary Agender/No gender Questioning
 Not listed. Please specify: _____ Don't know
 I don't know what this question is asking¹ I don't want to answer
-

3. Are you transgender?

- Yes No Don't know
 I don't know what this question is asking I don't want to answer
-

4. Please describe your sexual orientation or sexual identity in any way you want:

5. How do you describe your sexual orientation or sexual identity? (check all that apply)

- Same-gender loving Same-sex loving Lesbian Gay Bisexual
 Pansexual Straight (attracted mainly to or only to other gender(s) or sex(s))
 Asexual Queer Questioning Don't know
 Not listed. Please specify: _____
 I don't know what this question is asking I don't want to answer
-