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SCHOOL OF  
**PUBLIC HEALTH**

# REALD & SOGI DATA

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Please contact me if you feel you or your organization could benefit from my perspective and expertise with demographic data.

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These terms refer to **demographic data standards** developed by the Oregon Health Authority's Office of Equity & Inclusion through a community engaged process.

**REALD:** Race, Ethnicity, Language, and Disability

**SOGI:** Sexual Orientation and Gender Identity, and other aspects of sex, gender, and sexual behavior. SOGI is still a draft standard, but its development is well-advanced at this point.

Sometimes demographic standards around sex, sexual orientation and gender are termed SOGIE and SOGIESC in other jurisdictions and in the literature. There are nuances, but these refer to roughly the same thing when we are talking about demographic data.

## **A little about me**

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Transgender, transsexual

Social epidemiologist and activist

Collaboratively work for the just and accurate representation of people with sex, sexual orientation, and gender minority experiences (SSGM)

My collaborators on SOGI data include OHA, Oregon AETC's SOGI CoP, and ATHN. My collaborators are people with SSGM experience, BIPOC Oregonians, and PH professionals motivated by justice for SSGM.

I am a settler who is aware that ‘Oregon’ as an entity is built from land theft. My aspiration is to serve all people affected by Oregon’s policies on representing sex, sexual orientation, and gender. I hope my work fertilizes and expands efforts in policies for inclusive representation beyond the state of Oregon.

I humbly hope my work can support my Tribal and Indigenous colleagues and fellow community members.

While my demographic data work centers SOGI, I teach around racism, and my SOGI work intersects with REALD. I have the great privilege of collaborating with Marjorie McGee and her team at OHA who, with the help of community partners, have produced and continued to refine REALD. I hope to speak today with some small competence around the instrument.

Historical moment in Oregon: REALD and SOGI codified into law, and increasingly institutionalized.

Why this matters:

1. Accurately represent Oregon's diversity
2. Support inclusive practice and welcome in services
3. Striving for a society which does not systematically harm one population in favor of another; eliminate or ameliorate ongoing harms (i.e. get rid of 'avoidable differences' between groups).
4. More effectively identify those who may require group-specific services.

# Questions often come in two versions (SOGI)

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Many questions come in two versions—free text, and structured responses—and these serve overlapping & different purposes. E.g., some SOGI questions about sexual orientation:

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

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**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(es))
- Asexual     Queer     Questioning     Don't know
- Another identity not listed. Please specify: \_\_\_\_\_
- I don't know what this question is asking     I don't want to answer

# Questions often come in two versions (REALD)

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E.g., some REALD questions about race, ethnicity, tribal affiliation, country of origin, or ancestry (excerpt from a long form):

**How do you identify your race, ethnicity, tribal affiliation, country of origin, or ancestry:**

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

**American Indian & Alaska Native**

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

**Asian**

- Asian Indian
- Chinese
- Filipino/a
- Hmong

**Black & African American**

- African American
- African (*Black*)
- Caribbean (*Black*)
- Other Black

**Hispanic & Latino/a/x**

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

**Native Hawaiian & Pacific Islander**

- Chamorro
- Guamanian
- Microneasian/Marshallese/
- Palauan
- Native Hawaiian
- Samoan
- Tongan
- Other Pacific Islander

**Other Categories**

# The purposes of *free text & structured* responses

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## Free text responses

Center **patient/client** self-language & experience

Support **interpersonal connection**

Identify individuals with **group-specific needs**

## Structured responses

Support **demographic representation** at organizational and state levels

Let us **compare differences between groups'** access, outcomes, etc.;  
identify whether and which groups are being treated differently

Identify populations with **group-specific needs**



The idea that sex is binary, comprised of exactly two conditions—male or female—is a convenient fiction. Sex is both multi-dimensional—e.g., chromosomal, anatomical, physiological (hormone levels, dynamics, & receptors, Barr bodies, etc.), and legal (and varying by jurisdiction). Even at the level of discrete chromosomes, sex is *bimodal* not binary.

Practice is not there yet, but a patient's interests would be best met by representing sex using anatomy inventories and physiology inventories, without assuming that any particular answer precludes another. Of course, the validity of such inventories in *survey form* will be contingent on how much one can actually know about one's body.

**Important:** Separate questions included specifically for **ID matching** with the Social Security Administration, and legal sex in other jurisdictions.

# SOGI and *sex* 2: government documents

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## **When you were born what sex was assigned to you? (Pick one)**

- Male    Female    Intersex    Unspecified    Another sex not listed. Please specify: \_\_\_\_\_  
 Don't know    I don't know what this question is asking    I don't want to answer

## **What is your current legal sex in your state? (Pick one) (OR simply: What is your current sex?)**

- Male    Female    X    Intersex    Unspecified    Another sex not listed. Please specify: \_\_\_\_\_  
 Don't know    I don't know what this question is asking    I don't want to answer

## **If Yes [to question about state ID], what is the sex on your state-issued ID?**

- F – Female    M – Male    X, Non-Binary    U, Unspecified  
 Another sex not listed. Please specify: \_\_\_\_\_  
 Don't know    I don't know what this question is asking    I don't want to answer

**For federal reporting purposes if we were only given a binary option of M (Male) or F (Female), which one would you like us to use? –OR–**

**We respect and honor your gender. We use federal data to verify your information, like what you use for social security or on your passport. 2 They only offer two options – male or female. Please select the sex that matches your current federal information.**

- F – Female    M – Male

# **SOGI and *sex* 3: anatomy inventory best practices 10**

OHA's SOGI standard provides best practices for sex-related anatomy inventory:

**Are you (Check all that apply):**

- A person with breasts
- A person with a cervix
- A person with ovaries
- A person with a uterus
- A person with a vagina / vulva /clitoris
- A person with a penis
- A person with a foreskin
- A person with a prostate gland
- A person with testes
- A person with intersex genitalia
- A person who had genital reassignment surgery / bottom surgery
- Don't know
- I don't know what this question is asking
- I don't want to say

Common SOGI gender identities are **girl** or **woman**, and **boy** or **man**.

**Agender, Non-gender:** those rejecting masculine/feminine roles and identities, or even rejecting any participation in gender.

**Non-binary:** Some people occupy both masculine and feminine roles and identities, in androgyny (simultaneously masculine and feminine), through **fluid** expressions that are labile with internal or external contexts, and some through situational specificity (e.g., work gender vs. home gender). People with non-binary gender identities may or may not identify as agender.

The structured SOGI gender identity question also welcomes **multiple gender identities**.

Gender categories are culturally and linguistically specific. For example, **Two-Spirit** is a pan-North American indigenous non-binary or third gender label. (Not all North American indigenous individuals with transgender experience, or non-binary gender identity necessarily identify as Two-Spirit. Some South Pacific cultures have adopted the term Two-Spirit in a similar way.) There is recognition that if someone checks an identity in the American Indian & Alaska Native category on REALD, the Two-Spirit option should be made available for gender identity. There is a desire to not encourage appropriation of Two-Spirit by people outside the American Indian & Alaska Native community.

Community engagement and collaboration should inquire about similar links for other cultural groups. For example, Samoans, Thai, and other cultures have gender categories outside the binary prevalent in the USA.

**Gender modality** distinguishes **transgender**, **cisgender**, and **questioning** experiences.

Transgender means someone rejected or grew beyond their gender assigned at birth. Cisgender is its logical complement.

People whose gender identity is agender, non-binary, or who have multiple genders may or may not be transgender.

### Are you transgender?

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

**Caution:** Identifying sex assigned at birth and gender identity **are not** enough to determine whether someone is transgender. Separating transgender from (binary) sex at birth—as the OHA SOGI tool does explicitly—makes room to understand why people raised agender, or non-binary, may not identify as transgender. It also makes space to recognize that someone can simultaneously have male sex, and a masculine gender identity, yet still be transgender—for example when their experience is one of *gender transition* and they are on starting side of that journey.

Like sex, sexual orientation is multidimensional and varied in each dimension. For example, categories of sexual orientation can indicate attraction and desire, **self-identity**, **sexual behavior**, community affiliation, relational style or identity (e.g., monogamous, serially monogamous, polyamorous, non-monogamous), orientation towards categories of sexual behavior (kinky, vanilla, sensualist, etc.), orientation towards power (dominant, submissive, switch, etc.). ***Complicated!***

OHA's SOGI standard provides questions about sexual self-identity, and sexual activity, including about the anatomical characteristics of one's sexual partners.



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

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**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(es))
- Asexual     Queer     Questioning     Don't know
- Another identity not listed. Please specify: \_\_\_\_\_
- I don't know what this question is asking     I don't want to answer

**Pansexual:** A sexual self-identity open to partners of multiple genders or to partners of multiple sexes, and explicitly includes people with gender minority experiences (e.g., transgender, non-binary, etc.).

**Asexual:** An identity about being closed to sexual or romantic partners.

**Queer:** Not straight.

# **SOGI and *sexual orientation* 3: behavior best practices**

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**Are you sexually active?**

Yes    No

If No, have you been sexually active in the past year?    Yes    No

**If yes [to the above question]: Are your sexual partners (check all that apply):**

- A person with a penis
- A person with a vagina
- A person with intersex genitalia
- A person who had genital reassignment surgery
- Don't know
- I don't know what this question is asking
- I don't want to say

The OHA SOGI standard has questions about how people wish to be addressed. **Important:** *Honor* names, pronouns, and titles in communicating with & about the patient or client!

**What full name do you want to us to use? (Text field)**

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Is this your legal name?

Yes     No

If not, please list your legal name: \_\_\_\_\_

**Are there any other names we should know about, such as on your insurance card?**

Check here if there are other names we should know about

Legal name: \_\_\_\_\_

Name on insurance card: \_\_\_\_\_

Name on billing record: \_\_\_\_\_

Name on relevant previous medical records: \_\_\_\_\_

Name on other relevant records (Please specify): \_\_\_\_\_

**Important:** ‘Legal’ means from *any* jurisdiction, not merely ORDL!

When we consider minors of any age, and demographic data collection—especially SOGI demographic data—nuances come into play:

Track both (i) whether a parent or caretaker is answering for a minor, or whether the minor is answering, and (ii) if the other half of the parent/child dyad is present.

Adult SOGI questions should be appropriate to ask of minors about age 13 and up, but strive to give teenage minors privacy to answer, and also be transparent about what confidentiality you can provide or not provide regarding their demographic information (including to any parents).

Adult SOGI questions verge towards incoherent for younger minors. See [“Preliminary \(Year 1\) Report to OHA on Pediatric SOGI”](#) for guidance on questions for children under about 9, and for children ages 9–12.

Race and ethnicity data help us understand the experiences of populations based on identities constructed around heritage, nationality, culture.

REALD's racial & ethnic categories offer higher granularity than those used in the US Census, which helps include, welcome, and represent Oregon's true racial & ethnic diversity.

These categories also permit us to understand how well or poorly we are serving people across racial & ethnic categories.

REALD's questions about language help us best communicate and serve patients or clients, and also help us understand the experiences of groups defined by language ability (especially important for Oregon's immigrants!).

**What language or languages do you use at home? \_\_\_\_\_**

**Skip to question 7 if you indicated English only**

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

\_\_\_\_\_

**In what language do you want us to write to you? \_\_\_\_\_**

These questions will also help us identify our own staff language skill deficits and needs.

REALD's disability questions help our patients or clients disclose:

**Deafness or difficulty hearing**

**Blindness or difficulty seeing**

**Difficulty with mobility**

**Difficulty with concentration**

**Difficulty learning new things**

**Difficulty communicating**

**Difficulty completing errands alone**

**Difficulties resulting from emotion, mood, behavior, delusions or hallucinations**

These disabilities are important to disclose both because **they are in themselves important determinants of the health** of the individual, and because **they identify specific needs for the successful provision of health care and other services**. These categories also identify social locations that are important for understanding avoidable differences in access, outcomes, etc.

*Yes, but...*

Still need to **collect** the REALD and SOGI data, so collapse in **analysis**, not in the questions you ask.

**Be explicit** about which categories contribute to a grouping.

For example, if one wanted to report about a broad umbrella ‘Queer’ sexual orientation group, be sure to document or explain exactly which structured items mean one is in or not in that category (for example, does ‘Queer’ in your report include individuals identifying as Asexual? What about individuals identifying as ‘Straight’ but *also* identifying as another sexual orientation?).



Completing REALD & SOGI demographic forms:

Demands time! (*My first time with REALD took 12–15 minutes.*)

Is an emotional ask. There is vulnerability in these questions.

Raises questions of labor equity in demanding time & vulnerability.

Allow clients to **change their demographic data** on demand. This includes **allowing them to delete** demographic data.

Do not request updates more than once a year **across the entire provider system** (i.e. they should not have to fill out REALD and SOGI at the primary care provider, and then again at the specialists, and then again at the therapists, and then at the pharmacy, etc.).

# Do not assume REALD or SOGI responses are static 25

## People change across the life course.

A change in any REALD or SOGI response does not mean there must be an error. A change in race & ethnicity, or gender, or sexual orientation **should not** be automatically flagged as problematic.

For example, most of us who today enjoy good health and ability, with no disabilities to disclose simply have not lived long enough for that condition to have changed.

Centering active patient participation and autonomy in the clinic necessitates both empathy for the patient's needs and cultural humility.

Empathy is requisite both for valuing and understanding their immediate and long term health & health care needs, but also in terms of their relationship with a provider in a clinical context. (Researchers also!)

At the same time the provider's cultural humility in recognizing the limits of their own knowledge of the patient's experiences is a necessary part of a good-faith invitation to share in decision making.

Because our sexual biology is so socially laden with meaning, and because our gender experiences are for so many central to our immediate conceptions of self, we must strive for inclusion with SSGM, who historically have been systematically excluded from representation.

## Why this matters: Equity & sanctioned ignorance 27

We expect inequities in SSGM health relative to cisgender-binary health, because:

We have to educate our providers about our bodies and our genders, while in clinical settings,

We have to navigate health systems which often assume that it is fine to operate ignore our experiences and use the sex/gender binary,

We have more economic barriers to access, and often geographies of violence to navigate to access care and in the day to day.

“If you don’t know, you can’t act.”—epidemiologist Nancy Krieger

Providers, including those working the front desks, and designing systems **collect data:** Ask these questions. Help us see avoidable differences in health between groups. Help us learn about our communities’ needs.

Implementing these questions will invite push back. Some cisgender and binary gender persons will not see the point, or may respond with “Can’t you tell?” Some SSGM people will prefer to remain anonymous. Some people will become exercised at asking or being asked.

It will help to develop **response matrices** of scripted answers guiding people having these kinds of reactions back to the points: we try to make space for everyone; people of different sexes, genders, or gender modalities are treated differently (when they should not be), and this helps us be accountable; different people have different needs.

It was once verboten to ask a patient whether one had female sexual partners *and* whether one had male sexual partners, yet resistance to such questions has diminished, and such questions are now more commonplace in clinics.

**Question & Answer time!**

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## **[OHA web-page about REALD and SOGI](https://www.oregon.gov/oha/OEI/Pages/Demographics.aspx)**

<https://www.oregon.gov/oha/OEI/Pages/Demographics.aspx>

## **[OHA REALD resource](https://www.oregon.gov/oha/OEI/Pages/REALD.aspx)**

<https://www.oregon.gov/oha/OEI/Pages/REALD.aspx>

## **[OHA Draft SOGI standard](https://www.oregon.gov/oha/OEI/REALD%20Documents/DRAFT-SOGI-Recommendations.pdf)**

<https://www.oregon.gov/oha/OEI/REALD%20Documents/DRAFT-SOGI-Recommendations.pdf>

## **[40 Falsehoods programmers believe about names](https://www.kalzumeus.com/2010/06/17/falsehoods-programmers-believe-about-names/)**

<https://www.kalzumeus.com/2010/06/17/falsehoods-programmers-believe-about-names/>

## **[“Trans is my gender modality”](https://www.florenceashley.com/uploads/1/2/4/4/124439164/florence_ashley_trans_is_my_gender_modality.pdf)**

[https://www.florenceashley.com/uploads/1/2/4/4/124439164/florence\\_ashley\\_trans\\_is\\_my\\_gender\\_modality.pdf](https://www.florenceashley.com/uploads/1/2/4/4/124439164/florence_ashley_trans_is_my_gender_modality.pdf)

## **[“The Inclusivity Trap: Asking patients for their pronouns helps us treat them”](https://www.washingtonpost.com/outlook/2021/02/19/gender-pronouns-doctors-patients-medical/)**

<https://www.washingtonpost.com/outlook/2021/02/19/gender-pronouns-doctors-patients-medical/>

## **[AETC SOGI Community of Practice Draft Glossary](http://web.pdx.edu/~adinno/files/AETC%20SOGI%20Community%20of%20Practice%20DRAFT%20Glossary.pdf)**

<http://web.pdx.edu/~adinno/files/AETC%20SOGI%20Community%20of%20Practice%20DRAFT%20Glossary.pdf>

## **[“Preliminary \(Year 1\) Report to OHA on Pediatric SOGI”](https://archives.pdx.edu/ds/psu/37823)**

<https://archives.pdx.edu/ds/psu/37823>

## **[“Concerns about Safety of Minorities in the Collection of SOGI Data”](https://alexisdinno.com/files/ChaseDinno2022.pdf)**

<https://alexisdinno.com/files/ChaseDinno2022.pdf>