

# OHA/ODHS SOGI Committee Structure and Process used to Develop SOGI Data Recommendations (December 2021)

In 2018 the Oregon Health Authority (OHA) Equity and Inclusion Division convened the Sexual Orientation and Gender Identity (SOGI) Data Collection Committee. The group consists of internal and external stakeholders who interact with the LGBTQ+ community and health systems in a myriad of ways, many of whom also identify as LGBTQ+ themselves. The larger SOGI committee was stratified into six subcommittees, each focusing on a different level of implementation (see [Figure A](#)).

In early 2019, the committee began work on the standards for medical settings (Level 1 in [Figure A](#)), and then proceeded to draft recommendations for systems such as the Oregon Eligibility (ONE) system for Oregon Health Plan applications (Level 3 in [Figure A](#)).

The committee has also drafted [data collection standards](#) that will undergo in-depth review during rulemaking processes to add SOGI data collection standards to [OHA's REALD Oregon Administrative Rules](#) as required by House Bill 3159 (2021).

## Level 1 SOGI Data Survey Summary

### Background

Level 1 in [Figure A](#) focused on the clinical setting. The committee compiled the questions from intake forms of various LGBTQ+ serving clinics, and reviewed national best practices for asking SOGI questions. The committee's first round of community engagement invited feedback from LGBTQ+ community members at the Portland Q Center. Based on their feedback the committee revised the questions and moved on to the next phase of community engagement.

### Methods

For the next round of feedback, the committee created a web-based survey that:

- Asked respondents to rate the necessity of each of the proposed questions and associated answers.
- Provided a way to give open-ended feedback about the recommendations.
- Asked respondents for some basic demographic information, as well as their role in the health system.

The committee shared with organizations and clinics serving the LGBTQ+ community, as well as Oregon Department of Human Services (ODHS) workers, and asked clinics and organizations to share the survey with the people they serve.

### Results

Over 400 people accessed the survey. The committee assigned each question and response option, an overall approval rating expressed as a percentage of respondents who stated they would "Absolutely keep" or "Prefer to keep" the option. In the following tables, green cells indicate approval ratings of >75%, while red cells indicate approval rating of <50%.

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The committee also analyzed the approval rate for each question/answer option based on the sex/gender identity, race/ethnicity and professional role of the respondents. However, this analysis did not indicate a substantial difference from the approval rates calculated for all respondents. (For the purposes of this analysis, a professional is defined as someone who indicated they work as a clinician or researcher.)

Many respondents also included narrative responses to the prompts. (See Appendix A for key comments shared in the narrative responses).

### **Discussion**

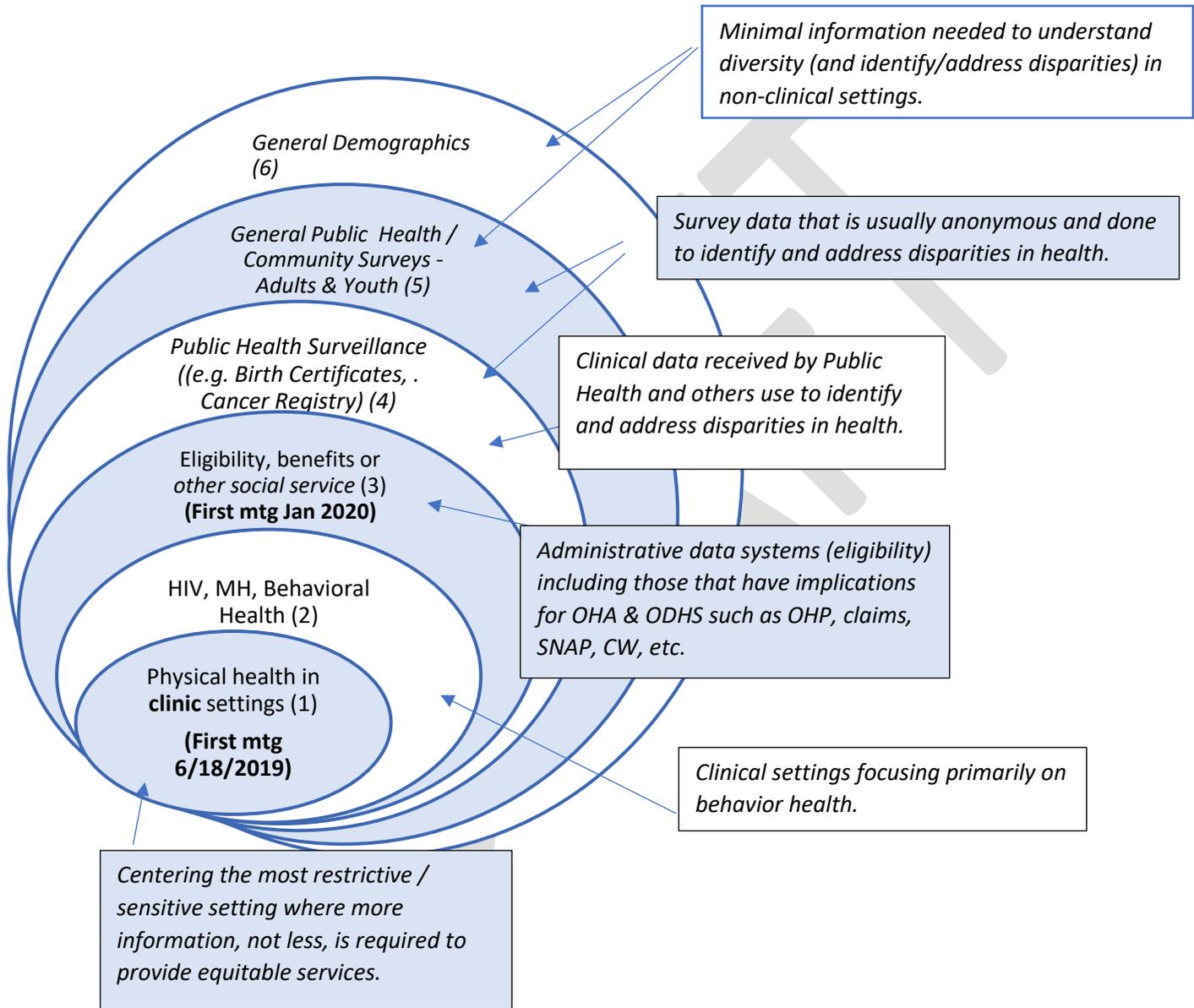
Most respondents favored most of the questions and response options offered in the survey. One notable exception was the question, "What title do you use?". Many respondents found this question to be outdated, even though many health systems do generate correspondence to patients using honorifics that are based solely on gender or sex and do not account for the patient's identity.

Many professional respondents commented that they would not want to ask these questions simply because it will create more work for them, not because they think the questions are not in the patient's best interest.

The most useful data may be found in the comments field for each proposed question. Respondents were able to provide more context about their answers and provide specific suggestions on what to change. The survey could have specified which questions would be asked of everyone, and which ones would only be asked as needed.

Figure A. SOGI Data Recommendations Process Diagram

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## Appendix A. Level 1 SOGI Data Survey - Results by Question

### General Demographic Questions

	Approval rate > 75%
	Approval rate 50-75%
	Approval rate < 50%

Question	All (n=230)	Trans, Nonbinary, Intersex (n=81)	Lesbian, Gay, Bisexual, Queer (n=137)	BIPOC (n=25)	Professional (n=61)	Not LGBTQ+ (n=60)
Please describe your gender in any way you prefer (open-ended question)	75.86	82.60	78.68	92.00	70.00	67.80
What is your gender? (Check all that apply)	81.37	76.30	83.09	91.70	86.70	79.66
• Woman or Girl	82.50	81.00	84.21	96.00	81.40	57.63
• Man or Boy	82.91	80.80	85.71	96.00	81.40	79.31
• Non-binary	86.14	88.80	90.3	100.00	78.30	77.59
• Agender/No Gender	80.69	86.30	82.09	92.00	71.70	77.97
• Feminine leaning	53.96	55.70	57.14	64.00	47.50	77.97
• Masculine leaning	55.39	57.00	59.26	64.00	47.50	45.00
• Questioning	72.41	81.30	77.61	96.00	60.70	45.00
• Not listed, Please Specify	82.81	86.10	88.46	100.00	80.70	61.67
Are you transgender?	66.18	67.60	72.26	76.00	65.00	72.22

Key Comments: “Ok so I rolled my eyes reading the first question but then I realized I'm a non-binary transmasculine person who is not ok being called a man (even though I love being referred to as "man" as in "hey man"). I do think healthcare providers should know if someone is transgender because of medical considerations.”

“Options should also include genderfluid, androgynous, and genderqueer.”

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	Approval rate > 75%
	Approval rate 50-75%
	Approval rate < 50%

Question	All (n=230)	Trans, Nonbinary, Intersex (n=81)	Lesbian, Gay, Bisexual, Queer (n=130)	BIPOC (n=25)	Professional (n=61)	Not LGBTQ+ (n=58)
Please describe your sexual orientation or sexual identity (open-ended question)	70.79	80.10	76.30	84.00	62.70	59.32
How do you describe your sexual orientation or sexual identity? (Check all that apply)	74.00	73.80	80.00	88.00	75.80	64.91
• Same-Gender Loving	55.73	62.20	59.84	72.00	46.50	50.00
• Lesbian	81.12	90.90	90.77	92.00	77.50	64.91
• Gay	81.22	88.30	90.84	92.00	79.30	66.67
• Bisexual	82.56	89.50	92.25	92.00	79.70	67.24
• Straight (attracted mainly to or only to other gender(s))	77.32	85.50	87.50	88.00	76.30	60.34
• Pansexual	73.98	85.60	83.85	88.00	71.20	56.90
• Asexual	76.56	88.00	87.50	88.00	71.40	57.14
• Queer	74.87	89.30	84.50	88.00	72.40	58.62
• Questioning	73.47	88.30	82.95	92.00	69.50	56.90
• Not listed, Please Specify	78.07	85.50	86.51	91.3	77.20	64.81

Key Comments: “Sexual orientation and sexuality are different, so we shouldn't ask these in the same question.”

“Some of these need definitions. This allows everyone to understand them, and for people to consistently be using the same definitions as they choose options.”

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**Logistical Questions**

	Approval rate > 75%
	Approval rate 50-75%
	Approval rate < 50%

Question	All (n=230)	Trans, Nonbinary, Intersex (n=81)	Lesbian, Gay, Bisexual, Queer (n=138)	BIPOC (n=25)	Professional (n=61)	Not LGBTQ+ (n=91)
Is this your legal name?	82.35	76.50	81.88	80.00	85.20	82.42
Are there any other names we should now about - such as on your insurance card?	87.01	88.80	88.89	86.90	91.50	86.21
Legal Name (with text to write in)	84.42	81.30	84.44	84.00	88.10	85.23
Name on insurance card (with text to write in)	87.88	88.90	89.63	96.00	86.90	87.36
Name on relevant previous medical records (with text to write it)	84.12	86.40	87.59	96.00	85.30	79.31
Name on other relevant records:	77.83	78.80	79.10	92.00	75.00	75.86

Key Comments: “As a trans person, changing your legal name is difficult, traumatic, and an extensive process that requires both time and effort. Adding a "name" question to health care documents takes little to no effort and would be a much-needed accommodation for transgender individuals.”

“It may also be helpful to include "Name used with family or caretakers," especially if patient is a minor or has any sort of caretaker or other party that may have legal access to medical records/medical information”

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	Approval rate > 75%
	Approval rate 50-75%
	Approval rate < 50%

Question	All (n=230)	Trans, Nonbinary, Intersex (n=81)	Lesbian, Gay, Bisexual, Queer (n=138)	BIPOC (n=25)	Professional (n=61)	Not LGBTQ+ (n=86)
What pronouns do you use?	93.13	97.50	97.10	100.00	91.70	87.21
• They/Them	90.35	96.30	94.85	100.00	86.20	84.34
• She/Her	92.11	95.10	95.52	100.00	89.90	88.24
• He/Him	91.74	95.10	96.32	100.00	89.90	85.88
• No pronouns, use my name	83.04	86.10	83.46	84.00	78.90	81.71
• Not listed, Please Specify	86.57	92.20	89.84	95.70	82.40	82.50

Key Comments: “I can't stress enough how important it is that health care settings use gender affirming pronouns. This includes health care workers (doctors, nurses, aides) and support staff like schedulers, check-in staff, etc. Everyone should be trained, retrained, evaluated...on using gender affirming language. Misgendering an individual could cause distrust, missed appointments, reinforce historic trauma, etc.”

“Some use two or more pronouns: so she/they, etc., should ask if they want to differentiate between pronouns for certain health related information. For an example, using "they" when talking about genitalia because using "she" may increase gender dysphoria.”

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	Approval rate > 75%
	Approval rate 50-75%
	Approval rate < 50%

Question	All (n=230)	Trans, Nonbinary, Intersex (n=81)	Lesbian, Gay, Bisexual, Queer (n=130)	BIPOC (n=25)	Professional (n=61)	Not LGBTQ+ (n=77)
What title do you use?	44.26	48.10	49.28	52.00	31.10	35.23
• Mx	59.53	73.10	68.46	62.50	45.60	47.37
• Ms	66.20	76.90	73.08	66.70	45.60	55.84
• Miss	55.81	64.10	58.46	66.70	38.60	51.32
• Mrs	57.21	66.20	63.08	70.90	43.90	47.37
• Mr	67.74	78.20	75.76	70.90	45.60	55.26
• Dr	60.47	70.10	67.69	62.50	47.40	50.00
• Honorable	39.17	46.10	40.15	39.10	29.80	36.84
• Please use my name and no titles	74.19	83.30	78.29	83.30	55.40	68.35
• Not listed, please specify	66.83	77.70	74.80	90.90	47.20	54.93

Key Comments: “If health systems are going to send mail or address things to a title, this question is necessary. I think the practice should be to not use titles, but that is a bigger change than what this question is asking.”

“Again, I think we should discourage providers from including titles when addressing mail or other documents. If these are mixed up it can be very offensive to the patient, and human error and bias can create mix-ups. This is true for non-binary and trans people, but also for cis women who get a title put on them because they marked "married" or "single" on a form.”

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	<b>Approval rate &gt; 75%</b>
	<b>Approval rate 50-75%</b>
	<b>Approval rate &lt; 50%</b>

Question	All (n=230)	Trans, Nonbinary, Intersex (n=81)	Lesbian, Gay, Bisexual, Queer (n=137)	BIPOC (n=25)	Professional (n=61)	Not LGBTQ+ (n=84)
When you were born what biological sex was assigned to you?	78.60	76.60	78.68	91.60	86.70	76.19
What is your current sex? (Pick one)	71.49	63.80	72.06	79.20	76.30	70.24
Do you have a state-issued ID?	64.76	71.60	71.53	75.00	57.60	53.66
If Yes, what is the sex on your state-issued ID?	57.89	65.50	64.23	79.10	53.30	46.34
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?	67.40	69.60	73.53	75.00	69.50	57.83

Key Comment: “I appreciate questions that clarify when talking about what's on my state issued ID versus what my gender/sex actually is. I also understand that federal options are extremely limited with regard to sex options, and appreciate the question making it clear that it's for data matching purposes.”

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Health-Related Questions (ask as needed)

- Approval rate > 75%
- Approval rate 50-75%
- Approval rate < 50%

Question	All (n=230)	Trans, Nonbinary, Intersex (n=81)	Lesbian, Gay, Bisexual, Queer (n=137)	BIPOC (n=25)	Professional (n=61)	Not LGBTQ+ (n=47)
Are you sexually active?	85.49	85.10	90.51	91.60	79.30	78.72
(follow up to previous) If no, have you been sexually active in the past?	82.54	81.00	86.67	91.30	79.30	78.26
(follow up to previous) If yes, question that then asks about body parts of sexual partner	62.63	60.00	65.69	73.90	67.20	60.00
• A person with a penis	67.36	73.40	74.26	76.00	66.70	55.10
• A person with a vagina	66.49	69.60	72.59	76.00	67.80	56.25
• A person with intersex genitalia	60.94	69.70	67.41	68.00	61.60	48.98
• A person who had genital reassignment surgery	50.00	51.30	54.07	52.00	53.30	44.90

Key Comments: “I would not answer questions about sexual activity outside the context of a trusted clinical encounter, not as an administrative intake process.”

“You should also follow this question with questions about types of sexual activity - a person may have partners with a penis but not engage in penetrative sex. Providers can make this assumption based on the genitalia of partners, and the conclusion they draw from assumptions can either lead to missed care or false/harmful assumptions.”

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	Approval rate > 75%
	Approval rate 50-75%
	Approval rate < 50%

Question	All (n=115)	Trans, Nonbinary, Intersex (n=80)	Lesbian, Gay, Bisexual, Queer (n=89)	BIPOC (n=13)	Professional (n=55)	Not LGBTQ+ (n=25)
Do you have any of these body parts?	78.05	85.20	86.52	85.70	72.90	57.69
When you were born, were any of these body parts present or expected to develop?	60.66	67.50	68.18	69.30	58.60	44.00
• Vagina	85.00	92.40	91.95	100.00	75.90	68.00
• Cervix	82.50	89.90	88.51	100.00	74.20	68.00
• Vulva	77.12	86.10	85.06	100.00	67.80	56.52
• Breasts	84.03	88.60	90.80	100.00	79.00	68.00
• Ovaries	83.33	89.90	89.66	100.00	75.90	68.00
• Uterus	84.17	91.20	90.80	100.00	75.90	68.00
• Penis	84.03	89.90	90.80	100.00	77.20	66.67
• Prostate	82.35	89.70	89.53	100.00	73.70	64.00
• Testes	82.50	88.60	88.51	100.00	75.90	68.00
• Intersex genitalia	80.67	84.80	86.21	84.60	75.50	66.67

Key Comments: “Absolutely necessary in healthcare settings to know if a patient has body parts that the provider may assume they don't have based on their gender presentation. Not to know that about a patient jeopardizes the patient's access to proper care.”

“Reading some of these makes me feel dysphoric. A lot of trans people especially won't want to answer this. We often don't like to call our body parts these terms. Also, some of us may not be totally aware of what we have or don't have. And again, what counts as a penis? What counts as breasts?”

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	<b>Approval rate &gt; 75%</b>
	<b>Approval rate 50-75%</b>
	<b>Approval rate &lt; 50%</b>

<b>Question</b>	<b>All (n=115)</b>	<b>Trans, Nonbinary, Intersex (n=80)</b>	<b>Lesbian, Gay, Bisexual, Queer (n=83)</b>	<b>BIPOC (n=13)</b>	<b>Professional (n=55)</b>	<b>Not LGBTQ+ (n=24)</b>
Are you currently taking gender-affirming hormones and/or hormone blockers?	91.38	97.40	96.43	100.00	85.70	79.17
(follow up to Q15) If No, are you interested in starting hormones?	83.93	92.10	90.24	100.00	73.10	63.64
If Yes to Question 15: when did you start?	85.84	90.90	91.67	100.00	83.00	71.43
If Yes to Question 15: what is your current dose and frequency?	86.84	92.30	92.86	100.00	83.00	76.19
Have you experienced any complications with hormones? [Q17]	85.22	90.90	91.67	92.30	81.80	73.91
If Yes to Question 17, what complications have you had?	84.35	90.90	90.48	100.00	78.20	73.91
Have you had any gender affirming surgeries/treatments in the past? [Q19]	88.50	96.00	95.06	100.00	81.50	73.91
(follow up to Q19) If Yes, which ones (list in text box)	85.71	90.80	90.36	100.00	80.80	76.19
If Yes to Question 19, do you wish to have further surgeries/treatments?	81.58	87.00	85.54	100.00	75.50	72.73

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Question	All (n=115)	Trans, Nonbinary, Intersex (n=80)	Lesbian, Gay, Bisexual, Queer (n=83)	BIPOC (n=13)	Professional (n=55)	Not LGBTQ+ (n=24)
(follow up to Q20) If Yes (to further surgeries /treatments), which ones? (list)	76.99	84.40	80.72	92.30	67.30	71.43
If No to Question 19, are you interested in having surgeries/treatments in the future	79.13	84.40	83.13	100.00	70.40	69.57
(follow up to Q21) If interested in future surgeries /treatments, which ones? (list)	74.77	81.40	79.01	92.30	67.30	68.18
Have you experienced any complications with gender-affirming surgeries/treatment	78.35	85.70	85.51	85.70	69.50	66.67
(follow up to Q22) If Yes, what complications have you had?	77.89	85.50	85.29	85.70	68.20	65.00
(follow up to Q22) Would you like to speak with someone with expertise in complications for this kind of surgery?	79.38	87.30	86.96	85.70	69.50	66.67

Key Comment: “A lot of these questions can also apply to intersex people. Strongly advise asking these questions to patients who indicate they are intersex; would also consider including a question asking if any surgeries were non-consensual. Many intersex people have received non-consensual, medically unnecessary surgeries that may lead to lifelong complications and/or trauma. Please review <https://interactadvocates.org/intersex-data-collection/> and include more specific questions on this survey (overall) for intersex people.”