

Preliminary (Year 1) Report to OHA on Pediatric SOGI

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Executive Summary

The report synthesizes the thinking and recommendations of the authors to OHA about routine data collection of SOGI data in minors for clinical and demographic purposes. Primary motivations to routinely collect SOGI data include: (1) inclusive practice in order to welcome and make space for people from historically excluded genders, sexes, and sexual orientations, (2) to promote health equity between minority and majority SOGI identities, and (3) to direct group-specific services towards those who need them.

Investigation and Findings

These recommendations are informed by (1) interviews with Oregon service providers and advocates for sex, sexual, and gender minority young people, and (2) a literature review to identify existing data sources on Oregon minors, and methods, and recommendations for collecting these data. The literature review yielded alarmingly few evidence-based recommendations for routine SOGI data collection for minors and sparse existing data on SSGM minors. Expertise gleaned from interviews with community advocates and service providers is incorporated throughout the recommendations below. Among considerations included in the report, we highlight the impact of parent/caregiver presence in data collection procedures, the need for cultural specificity in determining appropriate question and response options, individuals' right to have control over their data, and the value of open vs. structured questions which is dependent on age.

Summary of recommendations:

Age appropriateness: How questions should be asked and what response options should be provided may differ depending on the age and understanding of the child:

- For young children (under age 8 or 9) we recommend only using broad, open-ended questions and not involving structured, check-box style questions at all. If structured questions are necessary, we recommend a question that categorizes children's gendered experiences either in their own words or according to gender conformity or nonconformity.
- For children (ages 8 to 11) we still recommend focusing on open-ended questions, but these can be more specific, including questions about the body, attraction, and self-identifying.
- For adolescents (ages 12+) we recommend that the adult SOGI recommendations should be applied with special consideration given to ensuring that the adolescent understands the limits of confidentiality regarding this information.

Parental/caregiver report bias: To account for parent/caregiver bias in reporting minor demographic information, a flag can be used to identify who data is reported by.

Labor Equity: Because of the labor cost of reporting this data, we recommend that people are asked to fill out these forms no more than once per year. This poses technical challenges. Our recommendation is that a central database or repository is created, which holds demographic information for both children and adults. Healthcare and other service providers as well as researchers would be required to undergo appropriate training for respectful and ethical use of the data would then be able to request individuals' permission to access their SOGI data from this repository.

A preliminary note on language: Some terms used in this report may be unfamiliar, especially for people who do not work deeply around gender, sex, and sexual orientation. For a list of important terms and acronyms used in this report, see the glossary in Appendix 1. Terms appearing in the glossary will be marked with the symbol “†” at first use in the main text. We use the phrase “sex, sexual, and gender minority (SSGM†)” in place of the acronym “LGBTQ+”, because SSGM recognizes a commonly experienced system of structural and social marginalization that affects otherwise heterogeneous lived experiences of people with different genders, sexes, and sexual orientations.

I. Introduction

This document is a result of collaboration between the authors and the Oregon Health Authority (OHA) to improve existing guidelines for the collection of gender, sex, and sexual identity data (SOGI†) among minors (see Appendix 2 for relevant excerpts from OHA’s current draft SOGI guidelines for adults). This report synthesizes the thinking and recommendations of Martin Arrigotti, Kieran Chase and Alexis Dinno about routine collection of SOGI data in minors for clinical and demographic purposes.

Arrigotti performed the literature review and review of studies collecting SOGI data on Oregon minors, organized interviews with Oregon service providers and advocates of SSGM minors, how interview questions evolved, was an interviewer with Dinno, assisted in the IRB application for SSGM youth focus groups, and was the primary author of this report. Chase provided guidance in discussion of this report during its preparation, and was a collaborative editor and contributing author of the report. Dinno gave guidance to Arrigotti throughout all aspects of the project, helped organize interviews, was an interviewer, and was a senior and contributing author to this report. Dinno will serve as corresponding author.

Why collecting SOGI data for young people matters.

We see three primary motivations to routinely collect SOGI data: (1) inclusive practice in order to welcome and make space for people from historically excluded genders, sexes, and sexual orientations, (2) to promote health equity† between minority and majority SOGI identities, and (3) to direct group-specific services towards those who need them.

Individuals from minority genders†, minority sexes†, and from minority sexual orientations† have a storied history of exclusion from public spaces, public institutions, such as the right to marry a same-sex partner, and within service-providing institutions, such as health care, adoption or education, including in Oregon. One of the ways such exclusion operates is by a lack of representation—literally ‘not counting’ who is present. By implementing SOGI data standards that embrace diverse identities, including non-normative categories of gender, sex, and sexual orientation and sexual behaviors in structured demographic responses, as well as by placing free-text representations first, OHA’s SOGI tool can welcome minority representation and participation.

Health equity work is a critically important form of justice work engaged in by medical and public health professionals. Achieving health equity requires accurate and representative data about the populations involved (Whitehead, 1991), yet little such data exists for SSGM minors in Oregon or nationwide. Collecting data on SSGM minors in Oregon allows estimating the prevalence of various SOGI identities and positionalities, and which can allow more accurate

and reliable estimates of health disparities between SSGM minors and gender, sex, and sexual majority minors. Accurately estimating health inequities allows us to direct services and interventions to where they are most needed, and also to assess whether these interventions and services are effective, ensuring public health funds are appropriately and responsibly utilized to maximize health benefit.

Better standards for routine SOGI data collection with minors can promote equity in multiple governmental and private settings. In educational settings, it can be used to design sexed and anti-bullying curricula, or to identify if school policies or accommodations are failing to serve or harming specific groups of students. In the foster care system, understanding a minor's gender, sex, and sexual orientation is important for finding safe and appropriate foster care placement. Failure to do so could result in placing a SSGM minor in a household that is hostile, dismissive, or even potentially abusive. SOGI data collection can also help youth detention facilities ensure they are not increasing the risk experienced by detained SSGM minors. Any institution that interfaces with minors, especially in those settings that provide welfare, health, or educational services, will benefit from better SOGI data collection practices.

Finally, people in specific SOGI categories may have health needs specific to that group. As one example, gender-affirming health care services should be directed to transgender[†]-identified people. As another, health care services in support of reproductive health care, including obstetric care, should be directed to people who can become pregnant. Such needs also apply to non-health care settings as well: while there is a public good in all students' exposure to information about queer sexual and reproductive health as part of comprehensive sex education, sexual minority minors especially benefit from comprehensive sex education in schools which includes representations of their experience. Similarly, the absence of evidence for best practices of clinical or pharmaceutical treatment of transgender, or nonbinary[†] patients results from systematic erasure of these categories in research. For example, we cannot well answer basic clinically-relevant questions like “How to best ascertain risk and when to apply practices around drug-hormone interactions in individuals using gender affirming hormone therapy?”

We believe that, similar to the disability rights' concept of “universal design” (Steinfeld et al., 2012), wherein ensuring environments are accessible to those with disabilities creates benefits in accessibility for everyone, ensuring that SOGI data collection justly and accurately represents SSGM minors in Oregon will provide benefits in the form of representation and services for all minors in Oregon. As with OHA's REALD standards, we expect OHA's SOGI standards to create ripple effects promoting inclusive representation in non-public health disciplines and in other states.

OHA's approach to SOGI data collection, as informed by its community-driven process, (SOGI Data Standards Committee, 2022) has explicitly separated questions about gender identity from questions about gender modality[†] from questions about sex. This contrasts sharply with the so-called ‘two-question approach’ advocated by the Williams Institute (The GenIUSS Group, 2014) and recently by the National Academies of Science, Engineering, and Medicine, (National Academies of Science, Engineering, and Medicine, 2022) which biases the ways gender identity, gender modality, and sex—which all have some independence from one another—are represented to the harm of SSGM people (Morrison et al., 2021). In the past, and too frequently in the present, it has been common for demographic data collection practices,

both in clinical and research settings, to conflate gender and sex. Conflation of sex and gender threatens the validity of health equity research; by failing to adequately represent the experiences of gender and sex minorities, it may result in biased estimates of health disparities, or the failure to identify them at all (Morrison et al., 2021). In clinical settings, conflating sex and gender contributes to the stigmatization of SSGM experiences, sending two harmful messages. The first is that providers, by virtue of being unaware of SSGM experiences, are not likely to be knowledgeable of SSGM health concerns, therefore increasing medical mistrust and reducing access to care. The second is that there is not space for SSGM people in the clinic, that the exclusion of SSGM experiences in clinical data collection is intended to also act as an exclusion of SSGM people. Whether or not the intent is to exclude, then, the effect of conflation of sex and gender in demographic data collection is always exclusion, erasure, and marginalization of SSGM people.

II. Our Approach

We conducted a literature review using academic search engines, online university resources and government websites to identify: (1) What demographic data exists on Oregon minors, including the tools used to collect it, specifically surrounding gender, sex, and sexual orientation, and (2) What recommendations or research exists to improve routine SOGI data collection among minors. We met with professionals across the state of Oregon working in the service of queer young people, including both teens and young children. These included educators, advocates, care and service providers, and some of these were members of families with SSGM minors, or were SSGM themselves. From these professionals, we solicited informal input on how young people experience and think about their identities and positionalities, what are the best ways to collect these data, and what potential complications we may encounter (particularly around parent/caregiver and child relationships). We have submitted IRB documentation and are planning on conducting focus groups with SSGM minors to identify concerns or improvements that can be made on the recommendations laid out below.

III. Findings/gaps

The seven data sources we identified were: The Student Health Survey (SHS/OHT), the National Health and Nutrition Examination Survey (NHANES), the Youth Risk Behavior Surveillance System (YRBSS), the Healthcare Cost and Utilization Project (H-CUP): KID module, the National Health Interview Survey (NHIS), the National Survey of Children's Health (NSCH), and EHR data based-sources such as the national cancer registry or CHIP data. The YRBSS, was included in our work even though this survey is not administered in Oregon, because it is a national study, which is used by the neighboring states California, Idaho, and Nevada, although not by Oregon, that collects data about gender modality and sexual identity and behavior. See Appendix 3 for more details on these data sources.

Data on Oregon minors for gender, sex, and sexual orientation is sparse, or in the case of Oregonians under age 12, non-existent. Of the seven data sources we found collecting demographic information on Oregon minors, five do not collect SOGI data beyond fixed binary sex-gender. We found that one data source, the Student Health Survey (formerly the Oregon Healthy Teens Survey), provides far more comprehensive population level data on Oregon adolescents than any other state or nation-wide survey. Yet, as we detail below, even this

survey may not provide the comprehensiveness of data or precision of population estimates required to affect health equity for Oregon minors.

Table 1: Types of data collected, by source

Title	Data type	Sex	Gender	Sexual Identity	Age range
NHANES	Survey	Binary male/female only	Not collected	Not collected	0–17
SHS/OHT	Survey	Includes intersex or fill in the blank option	Includes diversity of gender options, distinguishes modality from identity	Includes information about sexual identity	8th and 11th grade (12–18 yrs old)
YRBSS	Survey	Binary male/female only	Distinguishes gender modality from gender identity, but treats gender as binary male/female	Collects information about sexual identity	Middle and High School (12–18 years old)
H-CUP: KID	Survey of Hospitals	Binary male/female only	Not collected	Not collected	0–17
NHIS	Survey	Binary male/female only	Not collected	Not collected	0–17
NSCH	Survey	Binary male/female only	Not collected	Not collected	0–17
EHR data	EHR	Binary male/female only*	Varies	Varies	0–17

* EHR data sometimes includes intersex, but the majority of this data will only include binary sex. See Appendix 3 for more details on these data sources.

Of the seven data sources we identified, there was one Oregon data source and five national data sources that collected demographic data on Oregon minors. Electronic health record (EHR) data was treated as a separate source of data, and was the only data source that did not come from a survey. Several government data sets—such as the national cancer registry, CHIP data, or the national syndromic surveillance system—use EHR data. Table 2 breaks down the number of studies that have any measure of gender or sex more inclusive than a binary male/female system. The number of studies that only have a binary male/female system and/or conflate sex and gender, and the number of studies that collect any information about sexual orientation from Oregon minors.

Table 2: Data availability for sex, sexual orientation, and gender.

Demographic Dimension	Number of Data Sources (N=7)	
	Children (<12 years) (n=5 data sources)	Adolescents (12–18 years) (n=7 data sources)
Gender, binary only OR conflates gender and sex	5	4
Gender, inclusive	0	2 (SHS, YRFBSS)
Sex, binary only	5	6
Sex, inclusive	0	1 (SHS)
Sexual Orientation	0	2 (SHS, YRFBSS)

In summary, few data sources are available on Oregon minors that distinguish between gender and sex, or which collect information about sexual orientation. Even fewer have more than 2 options for physiologic sex. Data on Oregon minors under age 12, except for that which conflates gender and sex and measures this only in binary terms, is non-existent. Bettering the health of SSGM minors in Oregon through inclusion, promoting health equity, and directing group-specific services is possible, but better routine data collection practices are required in order to do so.

IV. Key Considerations for SOGI Data Collection with Minors

Age appropriateness

How questions should be asked and what response options should be provided may differ depending on the age and understanding of the child. While research shows that awareness of gender minority experience can begin at a very young age (Rae et al., 2019; Zaliznyak et al., 2020), a 5-year old’s concept of gender, and the language they use to describe it, is almost certainly different than that of a 17-year old. Young children (i.e., children under 12 years-old) tend to speak about gender in more binary terms, and gender non-conforming young children may indicate that they do or do not feel that they are a boy, or that they wish they had different body parts, but may not understand questions about identity, or may not use language such as “transgender,” “nonbinary,” or “non-conforming” as frequently as adolescents or at all. Similarly, ‘transgender’ ‘cisgender’ and ‘questioning’, may have little meaning to very young people (i.e., children under 8 years old), but significantly more for teens. Questions of sexual identity likely have very different meanings for a child before and after they begin puberty.

We also question whether giving a parent or caregiver the choice of assigning these kinds of adult minority gender labels to their child would be a valid representation of the child’s self-representation of gender. For example, a parent may observe a young child’s behavior and interpret it to be flirtatious or indicating a specific sexual orientation or gender identity, when in fact the child is practicing or demonstrating mastery of social skills and the building of empathy for people in different circumstances.

Through puberty and adolescence, and through the aging process generally, minors become capable of more nuanced thought about gender, sex, and sexuality, and are likely to have begun to think about how well common labels, identities, and positionalities apply to their own experiences. Taking this developmental perspective into consideration, we believe that adolescents are similarly capable of understanding and interfacing with SOGI data collection instruments as adults.

Cultural specificity

Some examples of categories not well represented by current OHA SOGI guidelines, but which may have currency in particular geographic and ethnic contexts include the concept of detransition[†], the idea that transgender experiences together with sexual orientation describe facets of a singular identity, and SOGI-related labels from specific ethnic or cultural contexts. A useful tool in representing culturally specific identities would be linking options for structured gender identities and sexual orientations to REALD data, such that people who indicate certain racial or ethnic backgrounds will see additional potential responses on their SOGI forms. Some (non-exhaustive and non-comprehensive) examples of culturally specific identities include ‘Two-Spirit’ in American Indian and Alaskan Native contexts, ‘Bakla’ in Filipino contexts, ‘Māhū’ in Hawaiian or Tahitian contexts. Feedback from members of a variety of ethnic and cultural groups within Oregon would also be necessary to refine the connection between REALD and SOGI data.

Safety, transparency and child’s control over data

A difficulty in collecting demographic data from minors is that, under a certain age (which can vary depending on the data and the context in which it is collected, but roughly up until around age 15), parents/caregivers can legally access their children’s health information, and unless there is positive evidence of abuse, there is little minors can do to stop this. It is important to consider the safety of the minor when collecting demographic data from them, as well as transparently communicating what control minors have over their data, who it will be shared with, and how it will be used.

The safety of SSGM minors is also affected by an absence of representation in demographic data. For example, we have heard that in the state of Oregon, queerness in minors is not routinely tracked within the foster care system, nor is supportiveness of SSGM minors among prospective foster parents tracked, and this has led to SSGM minors being placed with hostile foster parents to their detriment.

Those who collect or access children’s SOGI data should be trained on how to utilize this data ethically and morally. We have heard of cases where a pediatric care coordinator asked preferred name and pronouns, then a few minutes later misgendered[†] or deadnamed[†] the minor in conversation with care providers and parents, ignoring the minor’s preference. Improper utilization—including the absence of practices to use and honor SOGI data—undermines the patient-provider relationship, the ethical validity of demographic data collection, and the safety of the child.

Parent/caregiver presence, power and bias

Protective, aware or unaware, supportive or unsupportive, or even hostile parents/caregivers will often misrepresent children’s SOGI identities in demographic data for a variety of reasons. This can bias estimates of the prevalence of children’s SSGM identities, resulting in underestimates of SSGM identity prevalences and overestimates of gender, sex, and sexual majority experiences and identities. Parents/caregivers of SSGM children will misrepresent children’s identities more often than parents/caregivers of straight, cisgender, sex majority children. Families have also been known to misrepresent SOGI demographic data of adults, especially in death records or when a person cannot speak for themselves (e.g., when they are in

a coma) (Dinno, 2017). This bias can't be resolved simply by backdating people's SOGI identities, or by comparing, for example, the prevalence of SSGM identities among 20-year olds to that among 16-year olds, because identity formation is a dynamic process, and just because the answer a parent/caregiver gave about a 16-year old does not match the answer the child gave later in life does not mean the parent/caregiver was misrepresenting their children's SOGI identities at the time.

Children do not always feel safe, and may not be safe, to share information about SOGI SSGM identities around their parents/caregivers. The presence of parents/caregivers when data is being collected, then, potentially biases representation of actual identity even when the data is collected directly from the child.

There is an emerging cultural trend towards gender expansive parenting[†], including some parents assigning agender or nonbinary gender to their newborns. This renders invalid any measures predicated on the assumption that all people are assigned binary gender at birth, or on the assumption that the sex on a child's legal documents is equivalent to their gender assigned at birth. Relatedly, it raises critical questions about who has agency in the passive voice construction "assigned at birth," and our stance, in line with the Yogyakarta Principles plus 10, is that everyone has a right "to express, through cultural participation, the diversity of [...] gender identity." (The International Panel of Experts in International Human Rights Law and on Sexual Orientation and Gender Identity, 2017).

Parents/caregivers, regardless of whether they are supportive, expansive, hostile, or ignorant of their children's SOGI identities, can generally only report on assigned gender, the child's most recent statements, observed behavior of the child, and assumed norms of attraction and sexual development. We should be careful not to conflate gender assigned or reported by others with an individual minor's gender identity or gender modality. Relying on parent/caregiver report assumes the parent/caregiver knows and would reliably report on the child's identities. This is an inherent limitation in parent reported SOGI demographic data, because gender identity and sexual orientation can only be valid when self-assigned. Neither Oregon, nor Federal law guarantees confidentiality of a minor's demographic information from their parent/caregiver. Similarly, neither Oregon, or Federal law guarantees a parent/caregiver access to their minor's demographic data. Therefore, OHA should explicitly recommending how minors' data is shared and protected, and should recommend transparency about such policy to minors.

Labor equity in providing data

How often we ask people to provide this data, and under what circumstances, has important implications for labor equity, access and ensuring that this health equity work is not harmful or counterproductive. Filling out demographic surveys takes time. Between OHA's REALD, SOGI, and various mental health and abuse screeners, the labor of providing this data could reasonably expect to take up to 30 minutes, and longer if a person has a disability or language barriers. The last thing we want is for data collection instruments aimed at promoting health equity to act as a barrier to accessing health care. Emerging consensus in OHA's SOGI development process, Oregon legislative rulemaking advisory committee process, and our consultation with community experts is that demographic information should be requested no more than once a year.

Many lived circumstances act as barriers to care and service. Onerous demographic data collection would exacerbate the barriers caused by, for example, working multiple jobs (especially jobs which are not accommodating of time off to acquire care or services), balancing transportation of school age children with work, mobility and transportation limitations. Language ability may also exacerbate the demand of demographic data collection, for example, people with visual impairment who require assistance reading, people with dyslexia, etc.. It seems to us that those who are most likely to be affected by the labor equity issues of routine data collection are those who are least able to absorb such impacts.

The value of open questions

Open questions (e.g., “in your own words, how would you describe your gender?”) center the patient-parent/caregiver dyad and are appropriate for all ages. They are also equally appropriate for collecting data from parents/caregivers and from minors themselves. They can be used to review how well structured (i.e., check-box) questions are capturing people’s lived experiences, giving the state of Oregon the institutionalized ability to recognize new, emerging, or unrepresented categories.

The answers to these person-centered questions will not always be useful in clinical or population health contexts. They will, however, establish that these are the kind of questions likely to be asked by clinicians and public health practitioners, which is useful in two ways. First, it lets both the child and parent/caregiver know there is space to talk to about their gender, sex, and sexuality, and that this space is inclusive of SSGM experience. Second, it lets parents/caregivers know that these are normal things for children to be thinking about or exploring. Both of which may have meaningful and positive impacts on the health of SSGM minors.

The value of structured questions

Structured questions provide quantitative data that can be used to estimate the prevalence of SOGI identities and positionalities among Oregon minors. From a clinical standpoint, this is helpful for identifying whether the percentage of patients with a given identity a clinic sees is unusual, potentially pointing to previously unnoticed or unmeasured risk factors or health disparities. The research results of these questions can also be helpful for clinicians to understand the relevant risk factors, policies, and health inequities that affect their patients’ health. Specific identities may inform the direction of group-specific clinical services. From a population or policy level, structured questions allow us to gather accurate estimates of health inequities, identify useful interventions or policy for achieving health equity, and evaluate the effectiveness of these interventions.

Public health surveillance demands structured data. For example, structured data would be required to estimate the top causes of death among transgender people, the top ten diseases affecting asexual people, the rates of bullying experienced by people in different categories of sexual orientation, etc.... all population health estimates we cannot currently make because we do not collect this data. The population health equity framework (Whitehead, 1991) demands comparisons of such population health measures to bring to light health disparities which may be caused by structural injustices and to strive for health equity. Therefore collecting inclusive SOGI data is requisite for health equity.

As previously noted, current sources of quantitative SOGI data for Oregon minors are scarce, and those that exist are incomplete. However, the SHS and a recent report by the Williams Institute (Herman et al., 2022) provide some estimates of population prevalences of Oregon minors with various SOGI identities. In the 2019 SHS, 6.1% of 8th graders and 5.5% of 11th graders identified as one or more non-binary or gender non-conforming gender identity, 9.9% of 8th graders and 12.6% of 11th graders in Oregon identified as gay, lesbian, or bisexual, and 0.3% of 8th graders and 11th graders indicated intersex or unclear sex at birth. Most analyses of this data exclude “something else” or “don’t know/not sure” from estimates of the number of LGBTQ+ minors, however another way to look at these results is that nearly 4% of youth in Oregon either don’t see themselves represented on these gender surveys or are currently unsure of their gender, and that 25% of 8th graders and 23% of 11th graders did not identify as straight or heterosexual (*Oregon Healthy Teens Survey, 2020*).

The Williams Institute also noted significant differences by age in estimates of prevalence of transgender identity. In Oregon, they estimated 1.18% of 13-17 year-olds and 1.54% of 18-25 year-olds identify as transgender, compared to around 0.5% of older age groups (Herman et al., 2022).

These estimates have limitations, and are likely to under-represent the true prevalence of SSGM experiences in Oregon minors. When the Williams Institute changed their process from imputing gender of minors from age trends of adults (Herman et al., 2017) to using recent data on minors collected in the YRBSS, their estimates of the prevalence of transgender identity among 13-17 year-olds doubled (Herman et al., 2022). It is likely that similar results can be expected from improving the accuracy and representativeness of SOGI data collection processes.

V. Recommendations

Some highlighted guiding assumptions

We assume SOGI data will be collected in the English language. Concepts and phenomena around gender cannot necessarily be assumed to translate seamlessly between languages. For example, Farsi has no gendered pronouns, Mandarin does in writing, but does not in speaking.

We also see cognition as requisite for gender identity, gender modality, and sexual orientation. For example, while a neonate may have an assigned gender, it cannot in any meaningful sense have a gender identity, gender modality, or sexual orientation. While we see cognition as requisite, we affirm that people of all types of neurology and cognitive development may have SSGM experiences. Neurodivergence or learning disability does not exclude one from any kind of gender identity, gender modality or sexual orientation. Someone who is severely obtunded cannot report gender identity, modality, or sexual orientation, and neither can they report anything else.

Data collection instrument

Young children (under age 8 or 9)

For children this young, we recommend *only* using open ended questions and not involving structured, check-box style questions at all. And we recommend these questions be broad, along the lines of “what should we know about your child’s gender?” and center the relationships in the service provider-parent/caregiver-child triad.

**For parents/caregivers:
What should we know about your child's gender?**

If structured questions are necessary for measuring young children's gender, we recommend a question that categorizes children's gendered experiences either in their own words or according to gender conformity or nonconformity. We have two potential recommendations for phrasing a structured gender question.

For children:

1. Are you a boy? Are you a girl? Are you both? Are you something else? Does it change?

OR

2. Are you currently

- A boy
- A girl
- Both
- Something else: _____
- It changes over time
- I don't know
- I don't want to say

For parents/caregivers:

2. Is your child currently

- A boy
- A girl
- Both
- Something else: _____
- It changes over time
- I don't know
- prefer not to say

We prefer "something else" to "neither" (which was suggested by Zucker & Wood (2011)) because this language avoids othering nonbinary gendered experiences. When speaking to children, we prefer "I don't want to say" to "I don't want to answer" or "prefer not to say" because this language seems more age appropriate for very young children. The explicit use of "are you" prior to each gender category also serves to avoid othering nonbinary gendered experiences (as opposed to "Are you a boy? Are you a girl? Something else?") The word "currently" and the phrase "it changes over time" may be sophisticated concepts about gender

and time for very young people, and therefore the first question might be preferable. A downside of both of these questions is that, while not explicitly stated to “check all that apply” or “check one,” children may be likely to interpret that these categories are exclusive, e.g., that one cannot be “both” and “something else.”

If a parent is present, the first question may be less likely to be activating to parents who are not gender expansive.

Children (ages 8 to 11)

For children ages 8 to 11, we still recommend focusing on open-ended questions, however these can be more specific, including questions about the body, attraction, and self-identifying.

For parents/caregivers:

1. What should we know about your child’s gender?

2. Is your child currently (for parents)

- A boy
- A girl
- Both
- Something else: _____
- It changes over time
- I don’t know
- prefer not to

2. Does your child get crushes?

- yes
- no
- unsure

For child:

Question 1 may allow a child to at this age to express their gender in their own words. Alternatively, the structured questions for children under age 9 years may also be appropriate. Both are listed here.

1. Do you know what gender is?

- yes**
- no**
- unsure**

1a. If yes, what is your gender?

1b. If no, ask question 2

2. Are you a boy? Are you a girl? Are you both? Are you something else? Does it change?

OR

3. Are you currently

- A boy**
- A girl**
- Both**
- Something else: _____**
- It changes over time**
- I don't know**
- I don't want to say**
- I don't know what this question is asking**

4. Do you get crushes?

- Yes**
- No**
- I don't know**
- I don't want to say**
- I don't know what this question is asking**

Adolescents (Age 12+)

We recommend the adult SOGI recommendations be applied to anyone over the age of 12. As mentioned earlier, there is an opportunity to tie SOGI to REALD responses, such that indicating a specific racial/ethnic identity on REALD could trigger culturally specific structured response options in SOGI for that person. Feedback from ethnic and cultural groups within Oregon will also be important to refine the connection between REALD and SOGI data forms.

There should be regular review of open-ended questions, and of any write-in answers for “not-listed” or “something else” to identify emerging categories of identity, or to identify common identities that are not currently represented. This iterative process is imperative for

ensuring data collection process accurately represent the lived realities of Oregon minors. Considering SOGI free-text responses in tandem with REALD data allows for analysis of unrepresented identities located in specific racial or ethnic groups.

We urge OHA to recommend that those collecting demographic information (including SOGI) from children should guarantee confidentiality for that information. We also urge that OHA recommend standardized and age-appropriate language indicating a lack of confidentiality when confidentiality about demographic information is not guaranteed by those who collect it.

Recommendation to Limit Parental/Caregiver Report Bias

To account for parent/caregiver report bias, a flag can be used to identify who data is reported by. This should apply to all demographic data, not just SOGI.

We assume that data may be acquired in-person or online (e.g., through an interface such as MyChart), and that some data flag indicates which manner an entry was collected in.

Collected by clinical staff or interviewer

If patient under 18

Q1: Data reported by

- Patient/Subject
- Parent/Caregiver
- Not listed (please specify): _____
- Unknown

If Patient/Subject, go to Q2

If Parent/Caregiver or Not listed, go to Q3

If form is filled out online, Q1 coded as "Online," Q 1.1 included in form.

Q2: Who was present with the patient/subject when the data was reported?

- Patient/Subject was alone
- Parent/Caregiver
- Not listed (please specify): _____
- Unknown

Q3: Was the patient/subject present when the data was reported?

- Yes
- No
- Unknown

Reported by patient/subject or parent/caregiver

Q1.1: Who is filling out this form?

- The Patient/Subject
- A Parent/Caregiver
- Not Listed (please specify): _____

If Patient/Subject, go to Q2

If Parent/Caregiver or Not listed, go to Q3

If form is filled out online, Q1 coded as "Online," Q 1.1 included in form.

Q2: Who was present with the patient/subject when the data was reported?

- Patient/Subject was alone
- Parent/Caregiver
- Not listed (please specify): _____
- Unknown

Q3: Was the patient/subject present when the data was reported?

- Yes
- No
- Unknown

Labor Equity and Centralized Demographic Repository

Because of the labor cost of reporting this data, we recommend that people are asked to fill out these forms no more than once per year. This poses certain technical challenges; how can different clinics know when the last time a patient was asked to provide this data was? What should a clinic or provider do if they need this data but it was recently collected elsewhere? How can a patient make changes when their personal circumstances have changed, but they do not want to have to make an appointment to see the specialist again just to change their information?

It is important that people have actual control over their data. Our recommendation is that a central database or repository is created, which holds demographic information for both children and adults (including REALD and SOGI) that health systems can request individuals' permission to access. Instead of providing this information at every visit, patients can sign a release to allow a clinic or provider to access their demographic information. We recommend, when possible, that minor assent to share demographic data (including SOGI) be designatable down to the specific provider level. For example, a large HMO shouldn't be able to mandate that every provider within their network gets the same access to demographic information. If demographic information has not been changed or confirmed in one year, patients/subjects may be invited to confirm or update. It is important that patients also have control over how and whether their data is stored, so patients should have the right to: (1) request their data be deleted from the database at any time, (2) make changes to the data at will, and (3) revoke consent for providers or clinics to access their data. If requesting personal demographic data be deleted from the database requires navigating bureaucratic hurdles, or if there is a long delay between

requests to modify data and this modification actually occurring, this undermines individuals' control over their data and potentially puts them at short term risk of inaccurate representation, and loss of privacy. Instead, changes should be able to be made online (through a program such as MyChart), and changes should be reflected as soon as they are made, which is to say, the system should be automated and networked.

Such a database would be useful for every institution that interfaces with minors, especially those which provide educational, health care, or welfare resources or services. The labor cost of reporting data is consistent across domains, i.e., it takes just as long to fill out SOGI and REALD at school as it does at the doctor's office, so allowing institutions to instead request consent to access already stored information has the potential to benefit patients in multiple aspects of their lives by reducing the frequency of requests to fill out data.

Another benefit of this suggestion is consistency and transferability of demographic data across multiple systems. People who have had to change their demographic information—a process which is not unique to SSGM people but is especially relevant to their lives—will often encounter a difficulty: it is possible for multiple institutions, including multiple different government agencies, to have conflicting demographic information on record, sometimes stalling their ability to access necessary resources and services. A centralized demographic data database would dramatically reduce the burden of changing legal documentation of a person's name, sex, gender, race, ethnicity, etc., which is frequently mentioned as a stressor or barriers to care for SSGM minors and their families (as well as SSGM adults).

There are privacy concerns related to setting up a demographic data repository. In the wrong hands, such information could be very dangerous. If a change in the Oregon government were to occur such that leaders wished to persecute SSGM people, this data could serve as a directory. Even in less severe circumstances, improper data safety management could pose risks to SSGM people in Oregon; a leak of this information, or if the database was compromised, could result in private demographic information falling into the hands of those who wish SSGM people harm. If the state requires or requests that institutions interfacing with SSGM minors collect this information, these security risks will exist no matter how they are stored. On the other hand, a central database, if managed correctly, is actually protective against the risk of loss of privacy, because there are fewer access points to be exploited. The trade off, then, is between a lower risk of data privacy breach and a greater number of people affected by said data privacy breach.

Limiting visibility of membership in a stigmatized group (such as gender, sex, and sexual minority) is a protective strategy. This strategy operates by degrees, from the "totally closeted" individual to people who are simply circumspect in specific contexts (e.g., at work, in public, in institutions such as health care or schools). Choosing to be 'closeted' widely or in narrow contexts is a legitimate means for queer individuals (but also families, professionals, and organizations) to secure themselves from many forms of homophobic, transphobic, and queerphobic violence. At the same time, the choice to closet itself perpetuates and normalizes stigmatizing homophobia, transphobia, and queerphobia. While the closet may offer some degree of protection, it also operates as violence against the self, whether or not the closet is total or situational (Meyer, 2003). Collecting SOGI data helps us decrease stigma by normalizing categories of social location in gender, sex, and sexual orientation in an effort to demarginalize for society as a whole, but may do little to protect individuals who are using the

closet as a protective strategy for their particular circumstances. We can compassionately recognize the ethical and moral value of limiting visible membership in stigmatized groups and at the same time recognize the ethical and moral value of demanding the opportunity for visible representation, including routinizing such visible representation in demographic data collection and in combating stigma.

Restrictions to accessing SOGI data

Two policy considerations when setting up a demographic data repository are who may access the data, and what levels of access should exist. While many institutions which provide services to minors (and adults) will be able to improve their services by requesting access to current SOGI data, fewer institutions will require historical SOGI data. We recommend that service providers who wish to access historical SOGI data (that is the history of changes to an individual's demographic information, including REALD), and who have obtained patient consent to do so, be required to document the reason for accessing such information, and that institutions are required to review the validity of these reasons, for example, through an IRB or IRB-like process, as often as needed (and where the IRB in question has received sensitivity and humility training around SOGI). The EHR software "Epic" has a function called "Break the Glass" that accomplishes this, so there is both precedent and existing software capability for such a system.

Service providers may have a variety of reasons for accessing historical demographic information. For example, engaging in IRB approved research that requires this data, or providing a treatment or service which requires knowledge of the ways a patient's body or the treatments they have received have changed over time. It also may be of use for long-term health care relationships or in systems such as foster care. Requiring service providers to document reasons for accessing historical demographic data serves as a checkpoint to help ensure patient data is being used safely and ethically, but is not dependent on a prescriptive list of what uses of data are legitimate.

Oregon law (OR 109.650) does not guarantee minors a right to confidentiality, nor does it guarantee parents a right to access their children's information. We recommend that service providers guaranteeing minors over age 12 must give permission in order for their information to be shared, even with parents/caregivers. In the short term, we recommend that the collection of this data come with an acknowledgment that confidentiality is not guaranteed, and that providers are trained to recognize situations when it is or isn't appropriate to share this information.

Recommendations about mandatory training

For accessing current SOGI data

Research ethics dictate that data must be collected with a purpose, and that collecting or accessing data without an intent to use it is unethical. For this reason, we recommend that workers and institutions who interface with minors should not be able to access SOGI data unless they have been trained on using the data respectfully. For example, a health care provider should know that if they collect data on pronouns and affirmed name, using the wrong pronouns or name is an unethical use of the data and has the potential to cause harm to patients as well as to undermine the practice of collecting SOGI data. We recommend OHA develop and

disseminate brief training materials around SOGI data use, to be guided by the three goals of inclusive practice, striving for health equity, and directing group-specific services where needed.

For accessing historical demographic data (including SOGI)

In addition to the training for accessing current SOGI data, we recommend that OHA create and disseminate training materials for institutions and individuals who desire to access historical demographic data (i.e. across the life course of the individual). These materials should be developed with input from advocates including social workers service SSGM children, TransActive, NARA, etc. These materials should include:

- (1) Training on SSGM populations (e.g., akin to what CITI offers for human subject training for LBGTQIA+ identities);
- (2) Training about intersections between the needs and vulnerabilities of minors with SOGI and SSGM specifically (for example, giving special emphasis on recognizing parent/caregiver-child power dynamics and the need to protect child from parents/caregivers, including when there is a service-provider involved).

For IRB members and others evaluating requests for access to historical demographic data

In addition to the training for accessing historical SOGI data, we recommend OHA create and disseminate guidelines for reviewers to:

- (1) Place special emphasis on recognizing parent/caregiver-child power dynamics, and the need to protect child from parents/caregivers, including when a service-provider is present, and attend to an applicant's attention to this dynamic;
- (2) Identify common misuses of historical demographic data.

VI. Conclusions

The health inequities affecting SSGM minors are deeply troubling from a moral and public health perspective. In order to identify actions that can reduce these inequities, and in order to ensure public health actions are as effective as possible, we need reliable, accurate data. Collecting SOGI data, then, is a public health good and a moral necessity. SOGI data has the potential to benefit individuals as well as population health. Services that interface with minors, including schools, clinics, foster care systems, and welfare systems, can all benefit from SOGI data. It can be used to provide better services, evaluate and ensure consistent quality of care, and perform critical justice work to improve the health of SSGM minors in Oregon.

Further work remains to: (1) solicit and evaluate the perspectives of Oregon SSGM minors age 14–17 into the final (Year 2) report through focus groups, under an already-approved IRB protocol; (2) to evaluate OHA's SOGI tool *in situ* as applied to minors; and (3) to address and integrate input from OHA's SOGI working group, and any of our interviewees.

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VI. Appendices

Appendix 1: Glossary

Cisgender: A gender modality in which a person’s gender identity is aligned with the gender assigned to them at birth.

Deadnaming: Using a name that a person has previously used to identify themselves but no longer uses, especially when the name change is the result of a change in a person’s outward-facing gender identity or expression.

Detransition, also de-transition: Some gender minority experiences are characterized by a typically long period identifying as a gender different than the gender assigned at birth, including with outward expression of the different gender, and then shifting away from this second gender. This can happen because someone grows into accord with the gender they were assigned at birth (e.g., detransition back to gender assigned at birth). This can also happen because someone grows into still a third gender (e.g., detransition to a nonbinary gender identity and/or expression). Anti-transgender and anti-gender minority individuals sometimes try to use detransition in arguments against affirming care, and against the legitimacy of a detransitioning or detransitioned person’s history with gender.

Gender assigned at birth: The presumed gender assigned by parents/caregivers, community, and society, typically but not always assigned on the basis of anatomical sex.

Gender expansive parenting: A style of parenting that is open to and/or supportive of the idea of gender nonconformity emerging in their children. In addition, some parents do not assign binary genders to their children at birth, instead choosing to assign agender/not assigning gender and/or assigning nonbinary gender, and may do so with the support of the communities in which their children are being raised.

Gender minority/majority: A categorization of gender identities and modalities that identifies whether or not a person’s gender identity conforms to socially prescribed and privileged concepts of gender (these privileged concepts being primarily “cisgender man” and “cisgender woman” in Oregon).

Gender modality: Describes an axis of experience with ‘transgender’ and ‘cisgender’ at either end, with ‘questioning’ being a middle option. We use the word ‘transgender’ to describe the rejection of or expansion beyond one’s gender assigned at birth, with ‘cisgender’ being the complementary notion of a sense of self in conformity with one’s gender assigned at birth.

Group-specific services: Resources (such as treatments, benefits, programs, etc.) which are intended to address the needs of a specific group. e.g., reproductive healthcare for people who can get pregnant, gender affirming care for people whose gender modality is not cisgender.

Health equity framework, also population health equity framework: As defined by Whitehead (1991), the health equity framework requires that we use data to identify health disparities between two populations, identify the social mechanisms that cause these disparities, and craft interventions to ameliorate or eliminate these disparities

Health inequity: A health disparity that is unjust, i.e., both unnecessary and unfair

Inclusive practice/inclusion: Welcoming all people and making explicit space for the full diversity of a population.

Misgendering: Referring to a person as a different gender than the one they identify as, especially when aware of the person's gender identity.

Nonbinary (gender identity), also non-binary, non binary, EnBy, enby: Some individuals identify neither as an exclusively feminine gender (e.g., woman, young woman, girl), nor as an exclusively masculine gender (e.g., man, young man, boy). For example, some specifically identify as a particular third gender (e.g., 'Two-Spirit', 'critter', 'unicorn', many others); some identify as agender (not all agender identify as nonbinary gender); some identify as a non-specified third gender; some identify as multiple genders (e.g., 'woman and man', gender fluid) at the same time, or at different times or in different contexts.

Questioning (gender identity): A gender identity that describes a person's state of exploring, developing, or changing gender identity.

Questioning (gender modality): A gender modality that describes a person's exploring, developing, or changing relationship between their gender identity and the gender assigned to them at birth

Questioning (sexual orientation): A sexual identity that describes a person's exploring, developing, or changing sexual orientation.

Sex assigned at birth: A categorization of a person's reproductive biology into a limited number of stereotyped categories (male/female, occasionally intersex), typically based on visible features of reproductive anatomy or karyotype.

Sex minority/majority: A categorization of people's physiologic sex that identifies whether or not a person's body conforms to the normative stereotyped categories of reproductive physiology and anatomy (i.e., how well a person's body fits into the prescribed categories of "male" and "female"). There are many ways to have a body that does not conform to stereotyped sex categories, some examples include, intersex conditions, gender affirming therapy or surgery, injury or surgical intervention (e.g., hysterectomy, mastectomy, orchiectomy to treat cancers), etc.

Sexual minority/majority: A categorization of people's sexual identities that identifies whether or not a person's sexual orientation conforms to socially prescribed and privileged concepts of sexuality (cis-normative heterosexual monogamous).

SOGI: Stands for "sexual orientation and gender identity," we also use it to reference gender modality, sex, aspects of sexual behavior, and gender expression.

SSGM: Sex, sexual, and gender minority. Each of the aspects of sex, sexual orientation, gender identity, and gender modality involve privileged positions. We use minority to indicate people occupying non-privileged positions (e.g., intersex people, asexual people, nonbinary people, transgender people). We add the additional "S" to expand upon the common abbreviation "SGM", indicating 'sex minority', to represent people whose bodies do not comport with stereotyped sex categories, which include intersex, but also people who have had gender affirming surgeries or therapies ("transsexuals"), people who had alterations to reproductive anatomy due to cancer, surgery, etc.

Transgender: A gender modality in which a person's gender identity rejects or expands beyond the gender assigned to them at birth.

Appendix 2: OHA’s adult SOGI instrument

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

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

- Woman/Girl
 - Man/Boy
 - Non-binary
 - Agender/No gender
 - Questioning **Note:** may change to ‘Questioning/Exploring’
 - Another gender 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
 - Questioning **Note:** may change to ‘Questioning/Exploring’
 - 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 **Note:** may change to ‘Questioning/Exploring’
 - Don’t know
 - Another sexual orientation not listed. Please specify: _____
 - I don’t know what this question is asking
 - I don’t want to answer
-

¹ “Don’t know” means the person doesn’t know (such as a parent answering for a child); “I don’t know what this question is asking” more to capture comprehension difficulties with the question and/or response options.

Appendix 3: data sources on Oregon children

Student Health Survey/Oregon Healthy Teens Survey (SHS)

Oregon Healthy Teens Survey. (2020). Oregon Health Authority.

<https://www.oregon.gov/oha/PH/BIRTHDEATHCERTIFICATES/SURVEYS/OREGONHEALTHYTEENS/Documents/2019/2019%20State%20of%20Oregon%20Profile%20Report.pdf>

The OHT is a biennial statewide study collected in public schools on 8th and 11th graders, weighted by county and school district. Gender is assessed with the question “how do you identify? (select one or more responses).” Options for gender identity are female, male, transgender female, transgender male, gender non-conforming, genderfluid/genderqueer, agender, unsure, and an open answer option. Notably absent are two-spirit and other culturally or ethnically specific gender options (outside of western culture-specific categories). Survey tables within OHT reports are stratified by male, female, or any non-binary/gender non-conforming gender. While the data itself allows for analysis of more specific gendered strata, small sample sizes for some genders may result in imprecise estimates.

Table 3: gender identity by grade in Oregon

Grade	8th	11th
	Weighted %	Weighted %
Female	48.5	48.1
Male	47.7	48.6
Transgender Female	0.3	0.3
Transgender Male	0.9	0.6
Gender Nonconforming	0.7	0.8
Gender Fluid/Genderqueer	1.0	1.0
Agender	0.4	0.5
Something else fits better (specify)	2.6	2.4
I am not sure of my gender identity	1.3	0.8
I do not know what this question is asking	1.2	1.0

The SHS assesses sexual identity with the question “Do you think of yourself as...,” and available responses are straight/heterosexual, lesbian or gay, bisexual, something else, and don’t know/not sure. Notably absent are any identities under the asexual umbrella, pansexual, or sexual identities which correspond to non-gendered experiences of attraction.

Table 4: sexual identity by grade in Oregon

	8 th grade	11 th grade
Lesbian or gay	2.0%	2.0%
Straight or heterosexual	75.0%	77.0%
Bisexual	7.9%	10.6%
Something else (specify)	7.0%	4.7%
Don't know/not sure	8.1%	4.9%

Youth Risk Behavior Surveillance System (YRBSS)

Underwood, J. M., Brener, N., Thornton, J., Harris, W., Bryan, L., Shanklin, S., Deputy, N., Roberts, A., Queen, B., & Chyen, D. (2020). Overview and Methods for the Youth Risk Behavior Surveillance System—United States, 2019. *MMWR Supplements*, 69. <https://doi.org/10.15585/mmwr.su6901a1>

The YRBSS includes an optional module that assesses gender identity and sexual orientation. Outside of Portland, Oregon does not participate in the YRBSS. However, the Williams Institute used data from nearby states to estimate prevalence of transgender gender identity in Oregon minors, estimating that 1.18% of Oregon minors age 13-17 years identify as transgender (Herman et al., 2022). Nationwide, the 2019 YRBSS found that 2.5% of high school students (age 13-17) identified as gay or lesbian, 8.7% as bisexual, and another 4.5% as unsure.

National Health and Nutrition Examination Survey (NHANES)

Centers for Disease Control and Prevention. (2020). National Health and Nutrition Examination Survey Questionnaire. U.S. Department of Health and Human Services. <https://wwwn.cdc.gov/nchs/nhanes/continuousnhanes/default.aspx?cycle=2017-2020>

Healthcare Cost and Utilization Project (H-CUP)

KID Description of Data Elements. (n.d.). Agency for Healthcare Research and Quality. Retrieved June 11, 2022, from <https://www.hcup-us.ahrq.gov/db/nation/kid/kiddde.jsp>

National Survey of Children's Health (NSCH)

Data Resource Center for Child & Adolescent Health. (2021). National Survey of Children's Health. U.S. Department of Health and Human Services. <https://www.childhealthdata.org/learn-about-the-nsch/survey-instruments>

National Health Interview Survey (NHIS)

Centers for Disease Control and Prevention. (2022). National Health Interview Survey. U.S. Department of Health and Human Services.
<https://www.cdc.gov/nchs/nhis/data-questionnaires-documentation.htm>

NHANES, H-CUP: KID, The NSCH, and the NHIS each conflate sex and gender, and provide only binary “male” and “female” options for both. These surveys do not include data on sexual orientation. NHANES and the NHIS include questions about gender identity and sexual orientation for people over age 18 years, but not for minors.

Electronic Health Record (EHR) Data

EHR data varies depending on what data the healthcare providers collecting it choose to collect. Recent Medicare and Medicaid requirements mandate that EHR programs (such as EPIC or THERAP) be able to collect sexual orientation and gender identity information, as well as to be able to separate gender identity from sex, but there is no requirement that providers utilize this capacity or collect this information (Brown, 2021; Cahill et al., 2016).