OREGON
HEALTH
AUTHORITY

OHA's Response to Public Comment OAR 950-030

In May 2024, the Oregon Health Authority sought public comment in response to proposed revisions to Oregon Administrative Rules 950-030. The proposed revisions were created in accordance with ORS 413.161. OHA convened a Rulemaking Advisory Committee (RAC) that convened from November 2023 to January 2024 to inform the proposed revisions. This Committee was made up of 25 individuals (see Table 1 below for more details).

Table 1: 2024 Rulemaking Advisory Committee Representation

Type of Representation	No.
Providers/Insurers/CCOs:	14
CCOs	4
Other insurers	3
Hospital Systems	4
Other Providers/Clinicians	3
Community Subject Matter Experts	12
REALD & SOGI overall & language	3
Race/ethnicity	2
Disability	1
SOGI	5
Total	25

Prior to the establishment of the RAC, OHA worked with community and health system partners since 2013 to develop and improve REALD. Additionally, OHA convened a SOGI committee in 2018 made up of external committee members to inform SOGI data collection standards. Please see here for more information on that process.

During the public comment period, OHA received 18 written and verbal comments representing perspectives from healthcare alliances, societies, and associations, as well as from health care providers, health systems, health insurers, nonprofit organizations, and private citizens (see Appendix A for a complete list). We reviewed all of the public comments submitted and applied changes to the final OARs as described below. Many comments expressed support for REALD and SOGI data collection, and several commenters appreciated the inclusive standards proposed by OHA. Copies of the full written comments will be provided on request.

The purpose of this document is to respond to the public comments. We are grateful to every individual and organization that took the time to provide thoughtful feedback regarding the proposed Oregon Administrative Rules. The REALD & SOGI data collection standards are more inclusive and effective thanks to your contributions, and we are eager to assist OHA partners and programs, coordinated care organizations, health care providers, and health insurers to implement these standards in pursuit of OHA's goal to eliminate health inequities by 2030.

See below for new and updated resources to assist implementing the updated Oregon Administrative Rules:

- Data Collection and Implementation Guidance for Data Owners Administrative
- At-a-Glance Templates – Providers are expected to use professional judgment to determine which of these two sets of questions to ask individuals aged 12 and 13 per OARs
  - Service Based Template for Age 12 and Up
  - Service Based Template for Under Age 12
  - Non-service Based Template for Age 12 and Up
  - Non-service Based Template for Under Age 12
- Summary of Race Ethnicity Changes
- Crosswalk
  - REALD Race Ethnicity TO OMB Crosswalk (use for federal reporting standards)
  - REALD SOGI TO HL7, HRSA and CMS SOGI Standards Crosswalks
- **Coming soon (check our webpage for an update in the next few weeks):**
  - REALD & SOGI Data Dictionary for Data Systems
  - CDC Race Ethnicity TO REALD Race Ethnicity (to use when sending OHA data in the future) cross walk
  - Updated CSV Reporting Specifications (APAC and current provider submissions to OHA)
  - Early this fall, OHA will publish an updated web based REALD & SOGI Implementation Guide and share updated resources and training materials for internal and external audiences.

If you have concerns or questions that you feel have not been adequately addressed, OHA welcomes your further input and engagement. You can reach the REALD & SOGI team at OHAREALD.Questions@odhsoha.oregon.gov.

The following summarize concerns raised in public comment and outline OHA's response to these concerns. Because many comments covered similar topics and concerns, we organized concerns and our responses by subject area, rather than responding to each commenter separately.

Public comment table of contents

General Comments

1. **Public Comment - A few commenters expressed concern about privacy and confidentiality related to how REALD & SOGI data will be shared. Commenters specifically indicated that patients need to be informed that their data is reported to OHA, how their data may be used, and that they're not required to submit data.**

Response - Thank you for your thoughtfulness in bringing this concern forward. Per ORS 413.164(3), providers, insurers and CCOs will be required to inform patients, clients, and members that their data will be reported to OHA, how their data may be used, and that the individual is not required to answer REALD & SOGI questions. The revised REALD & SOGI Implementation Guide will include recommended language to help inform people who are completing interviews, paper forms, and electronic forms.

2. **Public Comment - OHA received four comments requesting additional information about the economic impact of the proposed rule.**

Response - We understand that implementing revised data standards will have a financial impact on health systems, CCOs, providers, and other OHA contractors and subcontractors. We appreciate the comments that highlighted this factor. OHA will try to minimize the burden on health systems as much as possible. When developing the rules, we asked RAC members and others for

feedback on the economic impact of these change. OHA commissioned a fiscal impact statement, which provides information about anticipated costs that may be used by OHA divisions and contractors during their budgeting process.

3. **Public Comment - Three commenters expressed concern that OHA's requirements differ from other jurisdictions' data collection and reporting requirements. This was a particular concern for multi-state systems that will be required to collect and report data to multiple state-level regulatory bodies.**

Response - REALD & SOGI data is more detailed than is required by most state and federal agencies. This granular detail can generally be aggregated or "rolled up" to match other jurisdictions' requirements. See the crosswalks listed on page one, which allows data owners to map REALD and SOGI data to other jurisdictions' reporting standards. When data systems include the most granular requirements required from all current state and federal reporting requirements across states relevant to each data system, data owners will then be able to aggregate to meet different reporting needs. Our crosswalk (coming soon) from CDC race/ethnicity coding (which is already built into systems provided by certified EHR systems) to REALD race/ethnicity coding will provide an example of how this could be done.

4. **Public Comment - Five commenters requested greater flexibility around asking REALD and SOGI questions. Two of these commenters stated that the REALD & SOGI standards are not patient centered.**

   Commenters expressed concern that the requirement to ask all questions of all patients using the exact language in the OARs may fail to meet individual patients' needs, impair the patient-provider relationships, and inhibit provider discretion.

Response - We appreciate providers' concerns around meeting individual patients' needs and building and maintaining strong, trusting relationships with patients.

ORS 413.161(1) required OHA in collaboration with ODHS to establish uniform standards for REALD & SOGI data collection. Uniform standards include consistency in the wording of the questions and response options. This consistency allows for reliable data information collected across diverse contexts. Inconsistent wording would result in unreliable data that could not be used as effectively to identify and address health inequities.

In the Oregon Administrative Rules, we created flexibility for providers to take a patient-centered approach. For example, providers only need to ask the REALD & SOGI questions once a year, not at every appointment. They may ask using electronic forms, verbal interviews, or paper forms. They may ask in different contexts. This could be in-person during an appointment or on their own

time via an electronic form. Providers don't have to ask the questions all at once. Finally, people may choose not to answer any or all questions. We will continue to develop guidance and offer technical assistance to requestors working with populations that face additional barriers to answering REALD and SOGI questions.

5. **Public Comment - One commenter requested clarification about the timing requirement for annual data collection. The commenter asked whether the data needs to be collected once per calendar year, or on a rolling 12-month basis.**

Response - Thank you for letting us know that the timing requirement was unclear. REALD and SOGI questions need to be asked once every 12 months. If a record shows that a question was asked within the last 12 months—even if the answer was 'Don't know' or 'Don't want to answer'— requestors do not need to ask the question again during that 12-month period.

6. **Public Comment - One commenter voiced the need for a clear, easy option for patients to opt out of sharing REALD and SOGI information with other providers.**

Response - Thank you for highlighting patients' privacy. OHA receives data from providers and other groups required to collect and report REALD and SOGI data. However, we do not have the authority to mandate internal policies for entities (such as health systems) that display demographic information to different providers within internally managed systems (such as MyChart or other Electronic Health Records). We recommend that health systems create clear policies and practices for how they display and share demographic information. These policies might include ways for individuals to ensure their specific demographic details are not shared with other providers.

7. **Public Comment - One commenter requested that OHA include a definition of the term 'practicable' in the OARs.**

Response - The word practicable was not defined in the Oregon Administrative Rules. We were advised by legal counsel that a definition was not needed. Merriam-Webster defines practicable as: *"capable of being put into practice or of being done or accomplished."*

If a requestor subject to these rules is facing a specific barrier that may render implementing REALD and SOGI standards impracticable, the requestor can reach out to the OHA REALD & SOGI Governance Committee to receive guidance.

8. **Public Comment - Several commenters indicated that the proposed questions 1a and 1b, which established who was responding to the questions and who was present for the responses, were confusing and would be complex to implement. In addition, the initial template provided by OHA included the "date of birth" field in the same**

section, and commenters were confused about whether date of birth should be collected for the person the questions are about (who might be a child) or the person responding to the questions (who may be a parent or other caregiver).

Response - Thank you for bringing our attention to expected implementation challenges related to these questions about "proxy" reporting. This section was updated in the final Oregon Administrative Rules. We removed the proposed questions and replaced them with a single requirement: report whether the person answering the questions is "self" (the person the questions are about), "parent, guardian or other family member", "interpreter or other support person", or "Not listed, specify: (with open text box)". This question does not need to be asked directly if the requestor can determine the answer without asking.

People might share different information about their identities and experiences when others are present compared to when they are asked alone. Because of this, OHA will work with providers and communities to find a way to collect information about who is present when we gather REALD and SOGI data. We will address this topic in future rulemaking for REALD and SOGI.

Finally, for clarity: In cases where REALD and SOGI information about an individual is provided by someone else, OAR Chapter 950, Division 30 requires collecting the date of birth of the person the questions are about, *not* the person answering the questions.

9. **Public Comment - One commenter indicated that the requirement to capture and report the date when data is collected should apply to each question, rather than to the entire REALD and SOGI questionnaire in its entirety, because data may not all be collected in one session or on the same day.**

Response - Thank you for noting this. This is correct. Each instance when *any* REALD and SOGI information is collected should include a date stamp. For example, when asking a patient about their name, date of birth, and language during intake, their responses would be recorded with a date stamp. When asking disability questions at a later appointment, this is a separate instance of data collection, again with a date stamp. If the patient then fills out race/ethnicity and SOGI data via an electronic form following their appointment, this is a third instance of data collection with its own date stamp. If the patient later logs into their health record portal and updates their sexual orientation information, this is a fourth instance with another date stamp. Assuming all of these instances happen within the same reporting period, when the requestor reports data in a CSV, there should be four rows of data for this individual, each including the date of data collection and the responses given at that time.

During data processing, our system will combine these records to create a complete and up-to-date record for the individual with all data provided.

10. **Public Comment - One comment expressed concern that the updated OARs would not allow for asynchronous completion of the REALD & SOGI questions.**

Response - This is not accurate, and we appreciate having the opportunity to clarify this point. We do not restrict how data should be collected, as long as it follows the Americans with Disabilities Act and Title VI of the Civil Rights Act. Requestors can ask REALD and SOGI questions either "live" (like during an appointment or a phone interview) or asynchronously (such as using an electronic form sent via MyChart after an appointment).

11. **Public Comment - One commenter requested that the OARs speak to the applicability of the Americans with Disabilities Act to requestors' consideration of data collection methods, given the requirement that these methods must comply with the ADA.**

Response - The Americans with Disabilities Act of 1990 (updated in 2016) prohibits exclusion of persons with disabilities, indirectly or directly, from data collection because of their disability. Our team will create develop and share recommendations for accessible data collection practices.

12. **Public Comment - One commenter shared concern that the questionnaire is overall too lengthy for clinical settings. In particular, the commenter pointed to the free-text questions asking individuals to describe their identity in any way they prefer, which are closely followed by questions asking individuals to select their identities from a list of options. The commenter indicated that this structure is repetitive, and that patients often either become frustrated or simply skip questions they deem repetitive.**

Response - We appreciate your concern for patients' experience in completing the survey. We strive to balance the need to collect accurate, reliable information about people's experiences and identities with the need to make data collection as easy as possible for requestors and individuals.

Including open-ended questions allows individuals to describe themselves in any way they want, regardless of whether there is a matching check-box available on the form. This was an explicit ask from communities most impacted by health inequities. This is important for people who do not like labels or have identities that don't fit into the available categories.

The Oregon Administrative Rules allow a lot of flexibility to address concerns about the length of the survey. We only need to ask questions once every 12 months, not at every appointment, and we don't have to ask all of the questions at once. Plus, individuals can choose not to answer any or all questions, including ones they find repetitive.

13. **Public Comment - Two commenters indicated that the REALD & SOGI standards do not consider Electronic Medical Record platform functionality; in particular, one commenter was concerned about how standards would be implemented for EPIC users. Commenters voiced that the standards will be difficult to implement given existing EMR capabilities and limitations. Specific concern was raised that the lack of compatibility with existing standards would create a data silo, restricting interoperability and data sharing capacity, which could alienate patients and lead to duplicated questions.**

Response - We appreciate the need for effective integration of REALD & SOGI into existing EMR systems and data collection processes. We are committed to partnering with health systems to support implementation of REALD and SOGI, including integration into EMR software. We are working with some of our external partners to address implementation challenges and we are exploring options such as customizable APIs and FHIR to assist in data collection and transmission to OHA.

In a future rulemaking process, OHA will establish standards for securely transmitting and reporting REALD & SOGI data.

14. **Public Comment - One commenter indicated that January 2025 is too soon to require insurance companies to begin reporting REALD & SOGI data to the All Payers, All Claims system.**

Response - This concern has been shared with APAC. Adjusting the APAC reporting timeline is outside the scope of this rulemaking process.

15. **Public Comment - Two commenters requested the addition of language about privacy and security, either by referring to relevant legislation or administrative rules that govern the privacy and security of healthcare or insurer data that includes REALD & SOGI data, or by establishing specific rules governing privacy protections for REALD and SOGI data.**

Response - Thank you for your attention to the need for adequate privacy and security for those sharing potentially private and sensitive demographic information. The goal of this rulemaking process was to review and update standards for collecting REALD and SOGI data, as required by ORS 413.161. OHA will hold a future rulemaking process to adopt rules as required by ORS 413.164(3), including establishing standards for securely reporting and transmitting REALD and SOGI data.

According to ORS 413.164(4):

> *Data collected under this section is confidential and is not subject to disclosure under ORS 192.311 to 192.478. The authority may release the data collected under this*

section only if the data is anonymized and aggregated so that the data released does not reasonably allow an individual whose information is included in the data to be identified.

Data collected by OHA agencies and programs, as well as contractors and subcontractors, is currently protected by relevant data privacy laws governing data collection.

16. **Public Comment - One comment requested that OHA provide guidance about how to collect potentially sensitive REALD & SOGI data when an individual is in the company of others, especially those who have a legal right to access to the individual's health information (such as parents of children under 15 and court-appointed guardians). The commenter expressed concern about the potential to receive inaccurate responses to REALD & SOGI questions from individuals who may fear of another party's reaction.**

Response - We appreciate your concern for the wellbeing and privacy of people who provide sensitive information while answering REALD and SOGI questions. We recommend that prior to collecting REALD and SOGI data, requestors inform individuals about who can access their data. When collecting data from minors, make sure to clearly explain that parents or guardians might have access to their data. In future implementation materials and training curricula, our team will include information about trauma-informed care and trauma-informed data collection practices, so that requestors are aware of strategies for collecting data when privacy—both in terms of data storage and in terms of data collection—cannot be guaranteed.

17. **Public Comment - Two commenters asked for clarity on the timeline for implementation, and specifically, when data submission will be "required" vs. "encouraged".**

Response - Those submitting data through All Payers, All Claims should refer to APAC's implementation timeline. For any contractor or subcontractor who does not submit data through APAC, compliance will not be required until OHA has completed the data repository and registry system, which is currently expected to happen in late 2026 or early 2027. Agencies, programs, contractors, and subcontractors are encouraged to begin submitting data as early as possible (in CSV format).

18. **Public Comment - One commenter indicated that the language on the Templates informing individuals that they may skip questions is misleading, because they are required to respond with "Don't know" or "Don't want to answer".**

Response - Thank you for bringing this to our attention. The language has been updated as follows, for clarity:

> *To help us better understand your health care needs, we need to know some things about you, like your race, language, gender, and ability levels. While we hope you answer these questions, you can select "Don't know" or "Don't want to answer". Your responses are confidential.*

19. **Public Comment - Several commenters who referenced the Simple Templates published by OHA were under the impression that these forms represented the only compliant method of data collection and expressed concern about specific formatting and other details on the Templates.**

Response - We are grateful for the diligence of commenters who want to ensure that data collection is flexible across different settings. Requestors don't have to use forms produced by OHA. The printable templates are designed for different settings, including separate ones for adults and children in service-based and non-service-based settings, which can be found linked in the resource list on page 2 of this report.

These templates may be:
- Printed to collect handwritten responses to REALD & SOGI questions.
- Used to ensure language access. We are currently in the process of translating our templates into 20 languages. Email us at OHAREALD.Questions@odhsoha.oregon.gov to request a specific language translation that is not already available. These translations can also be used to implement in electronic systems.
- Used as an at-a-glance reference for the REALD & SOGI data categories and questions.
- Reformatted to fit the data collection tool used by the requestor.
- Referenced to help maintain fidelity of interpreted or translated questions.

Note that data requestors can integrate REALD & SOGI data collection standards into their existing systems, including electronic forms and live interviews, as long as the data collection follows the Oregon Administrative Rules set by this rulemaking process. The REALD and SOGI team has templates in Qualtrics and we will be updating the Patient Facing Survey Tool. Please email OHAREALD.Questions@odhsoha.oregon.gov to inquire.

20. **Public Comment - One commenter indicated that the questions about proxy reporting should be moved to the end of the questionnaire, because this information is less important than the demographic information.**

Response - This question, which does not provide demographic information, is best placed with other logistical questions like the date, date of birth, and name of the individual. However, requestors can gather proxy reporting information at any point during data collection.

21. **Public Comment - One commenter indicated that there should be separate forms for children and adults.**

Response - Thank you for this recommendation. In response, we created separate forms for children and adults in both service-based and non-service-based settings. Using one form for both age groups would make the survey confusing and tiring. We recommend that requestors who serve both children and adults and use paper forms should use separate forms for each group.

22. **Public Comment - One commenter was confused about why the template included "don't know" and "don't want to answer" options for all questions, but this was not clearly required for electronic forms according to the Oregon Administrative Rules.**

Response - Thank you for asking this question. The Oregon Administrative Rules don't explicitly list these options under each question. However, OAR 950-030-0020(6) states:

"For all REALD and SOGI questions, except for open-ended text questions, a requestor must offer the following response options in addition to any other responses required in these rules:

(a) "Don't want to answer". This response should be used by an individual or the individual's caregiver when the individual or caregiver is choosing not to answer the question.

(b) "Don't know". This response should be used by an individual or an individual's caregiver when the individual or caregiver does not know the answer to the question."

This requirement applies for all questions in the REALD & SOGI survey (except those with free text responses) regardless of whether it is administered using a paper form, electronic form, or verbal interview.

Language

1. **Public Comment - Two commenters brought forward concerns about the requirement to use the full list of languages in the ISO 639-3 standards. The specific issues**

brought forward include lack of compatibility with existing EHR/electronic form software and the inclusion of inactive or non-living languages in the ISO 639-3 standards.

Response - Thank you for bringing forward concerns about using the full list of languages in the ISO 639-3 standards, including issues with compatibility and the inclusion of inactive or non-living languages. We have updated OAR 950-030-0040 to indicate the following:

> *(5) Requestors who are collecting language data electronically using the ISO 639-3 standard and who are able to use auto-completion or smart filtering capabilities must use the full ISO code list provided by OHA, which includes relevant local codes.*

> *(6) Requestors who are collecting language data electronically using the ISO 639-3 standard and who are not able to use auto-completion or smart filtering capabilities must use the abridged ISO code list provided by OHA.*

> *(7) If a requestor uses technology that limits their ability to implement section (6) of this rule, a requestor must contact the Oregon Health Authority REALD and SOGI Governance Committee to receive guidance on acceptable alternative(s).*

The full ISO code list provided by OHA includes local codes and allows participants to select from over 7,000 languages. The list is filtered to include only active, living languages. If you have additional needs outside of active, living languages, please contact us at: OHAREALD.Questions@odhsoha.oregon.gov.

The ISO list works best with the use of smart filtering. When a person types the name of the language, matching language(s) will show up for the person to select. For example, if a person types "Japa", the six languages in the list containing those letters will appear in a dropdown for the person to select from. Using the ISO 693-3 list we provide is the preferred method for data collection because it has detailed information to help requestors find the correct translation and interpretation services. Our team can provide technical assistance and guidance on how to use the full ISO code list.

For requestors using a paper form, language information may be collected using an open-text box. For requestors using an electronic form that is not capable of smart filtering the entire ISO code list, we have a shorter list of languages found in the REALD & SOGI Data Dictionary (coming soon).

2. **Public Comment - OHA received two comments voicing concern about the reading level of the REALD & SOGI questions. Commenters indicated that the survey is currently written at 10th to 11th grade reading level. The commenters indicated that the**

survey needs to be at a 6ᵗʰ to 8ᵗʰ grade reading level to be consistent with their existing practices.

Response - We appreciate your consideration for making sure the survey is accessible. We have reviewed and updated several parts of the REALD & SOGI questions. We did this to make them easier to understand. The survey reads between a 6th and 8th grade reading level in key sections. However, there were some limitations primarily in the disability questions because of the number of syllables in some of the words such as "difficulty." Most of the disability questions came from validated instruments and are used by the Census and other federal government programs. We cannot change these questions because they allow us to compare Oregon's data to national data. In other sections, including SOGI, we used language requested and vetted by communities. These decisions may affect readability levels, but the language is generally well-understood by individuals who hold these identities, and therefore meets community needs.

3. **Public Comment - Two commenters voiced concerns about questions identifying needs for translation and interpretation services. One commenter indicated that these questions extend beyond demographic data collection and would interact with or interrupt existing institutional policies and workflows related to requesting translation and interpretation services. Another commenter was concerned that these questions imply that a requestor will meet the indicated need, regardless of capacity.**

Response - Thank you for highlighting concerns about how the Language standards may interact with existing processes. Language, English skills, and translation needs are demographic factors that affect how people get healthcare. It's important to collect this information to find and fix health problems for those who have trouble with language. These questions aren't meant to replace other request processes, but they can be part of the process to find out who needs translation and interpretation services. If requestors can't add these questions to their current system, OHA suggests adding a note to the questionnaire telling people how to ask for translation services. Note that individuals accessing healthcare services have a right to translation and interpretation services under Title VI of the Civil Rights Act.

4. **Public Comment - One commenter stated that asking the question "Do you only use English at home" regardless of the language in which survey is administered assumes English as the default language and is therefore English-centric and not inclusive.**

Response - Thank you for this note. This question is similar to questions in other national surveys like the American Community Survey and thus helps with comparability. Further, this question is a triage question affording the ability to leverage skip logic to reduce survey fatigue. Sometimes, a person using a translated survey might say they only speak English at home, even if they know

another language. For example, they might be the only one in their household who speaks the survey language.

5. **Public Comment - One commenter pointed out that FM, Loop, and CART/captioning are assistive devices and services, not interpreters, and should be addressed separately from language interpretation.**

Response - Thank you for pointing this out. We have adjusted the survey to separate questions about assistive listening devices and CART/captioning needs (1b on the adult template) from language interpretation needs (2e).

6. **Public Comment - Two comments voiced concern about a response option "Certified Deaf Interpreter for Deafblind, additional barriers, or both" for the question asking individuals to select which type of interpreter they need or want. One comment pointed out that "additional barriers" is not a type of interpreter, while another indicated that there is not a need to identify who the interpreter is intended to support—i.e., that "Certified Deaf Interpreter" would be sufficient, and the explanation "for DeafBlind, additional barriers, or both" is not needed.**

Response - We appreciate having the opportunity to clarify the need for this response option. We included "DeafBlind, additional barriers or both" to honor a request made by members of the Deaf community. To clarify, a CDI has a different role than an ASL interpreter. Some people may need a Certified Deaf Interpreter (CDI) such as some DeafBlind people, those who use a local sign language, or D/deaf people who have trouble signing or who uses home sign but not ASL or another formal sign language. In summary, a CDI is a Deaf professional with advanced communication training and skills who works with a hearing sign language interpreter to help with communication.

Disability

1. **Public Comment - One commenter expressed concern that the following open-text question was too broad in scope, and that responses require follow-up from requestors that could be difficult to track or address: "If you identify as someone with a disability, or as having a physical, mental, emotional, cognitive, or intellectual condition, what would you like us to know?"**

Response - We use this open-text question to match similar questions in REALD & SOGI about Race/Ethnicity, Sexual Orientation, and Gender Identity. These questions let people describe

themselves in any way they want, even if there isn't a box to check that fits their experiences or identities.

We know the original question might have been too broad to get the right information. We changed it to: "If you identify as someone with a disability, or as having a physical, mental, emotional, cognitive, or intellectual condition, describe your disability or condition in any way you prefer: (open text)"

This question is very important for collecting disability data. Many people with functional limitations do not use the word 'disabled'. Also, the experiences of many people who identify as 'disabled' or as 'having a disability' are not captured by questions about functional limitations and accommodations.

2. **Public Comment - Two commenters voiced concerns about the question asking individuals to list desired or needed disability-related accommodations. Specifically, one concern was that the open-text question was too broad, and the responses would not be useful for identifying either individual accommodations needs or population health inequities. Another concern was that the language of the question implied that the requestor would meet any accommodation request identified by the individual, with no ability to restrict responses to a list of available accommodations.**

Response - Thank you for your concern about the intention and impact of this question. We updated the accommodations question to: "If you identify as someone with a disability, or as having a physical, mental, emotional, cognitive, or intellectual condition, do you need or want disability-related accommodations?" If someone answers "Yes" they are asked to select all that apply from a list of types of accommodations (such as alternate formats, communication access, and equipment access) and to provide any extra details using open-text boxes.

We made this change to address the concern that the question was too broad. It helps clarify what we mean by "accommodations" and gives structure to help people understand how to answer. This also helps requestors to anticipate possible responses.

Note that the disability questions in this survey are not meant to be a formal request for accommodations. We recommend that requestors add an access statement at the beginning of any survey or form that clearly indicates how respondents can submit a formal accommodations request, as required by the ADA.

Collecting information about accommodations in REALD & SOGI is a new practice in the updated Oregon Administrative Rules. Our data dictionary (coming soon) will include an accommodation

code list with accommodation types that can be used in lieu of offering free text. This could also be used to help partners plan for future needs within data systems and service settings.

3. **Public Comment - Two commenters voiced concerns about questions identifying needs for disability-related accommodations. One commenter indicated that these questions extend beyond demographic data collection and would interact with or interrupt existing institutional policies and workflows related to requesting reasonable accommodations. Another commenter was concerned that these questions imply that a requestor will meet the indicated need, regardless of capacity.**

Response - We appreciate your concern around how these questions will be integrated with existing systems. Disability-related access needs are demographic factors that affect how people get care. It is important to collect this information to identify and address health inequities faced by those who have unmet access needs. Collecting only data on functional limitations does not show all access needs. Each person has unique access needs and barriers, even within the same functional limitation groups. Gathering data on accommodations can help us identify barriers and environmental factors to address health inequities.

These questions are not meant to be formal requests for accommodations, but we can use them to identify people with access needs. If requestors are not able to adjust their current workflows to include responses to the REALD & SOGI disability-related accommodations questions, we recommend adding instructions to the questionnaire on how people can request services. However, people using healthcare services have a right to reasonable accommodations under the Americans with Disabilities Act.

Race and Ethnicity

1. **Public Comment - One commenter requested that the heading "Middle Eastern/North African" (MENA) should be changed to "Southwest Asian/North African" (SWANA), to align with the emerging community-based term. The commenter indicated that SWANA is a less Euro-centric way of describing the region than MENA.**

Response - Thank you for this comment and request. We have also noticed that community members are increasingly using SWANA. During this rulemaking process, we updated the Race and Ethnicity questions for two reasons: (a) to reflect input from communities and (b) to align with the new federal OMB race and ethnicity data collection standards that were issued in Spring 2024. We need to retain the "Middle Eastern/North African" heading to align with the updated federal standard; however, we have also added "SWANA" to honor the perspectives of the communities represented by this heading. The new heading reads "Middle Eastern/North African/SWANA." We are grateful for the opportunity to align our work with community.

2. **Public Comment - One commenter indicated that the 9 open-text fields included in the question asking participants to select their race/ethnicity would be a significant burden requiring too much data review and processing for system administrators.**

Response - Thank you for your comment and for considering the burden that open-text fields might place on internal and external analysts. This update lets individuals provide details about their race/ethnicity within each parent category and aligns with recent federal guidelines for collecting race and ethnicity data. Our team will create implementation resources to support requestors in efficiently storing and processing the open-text data, as needed.

In addition, we added the following language to OAR 950-030-0030(4): *"If a requestor uses technology that limits their ability to store data from any of the open text boxes listed in section (2) of this rule, a requestor must contact the OHA REALD & SOGI Governance Committee to receive guidance on acceptable alternative(s)."* We hope that this addresses the concerns brought up by the comment and we will ensure that implementation resources are effective in supporting analysts.

3. **Public Comment - One commenter requested that the heading "American Indian" should be changed to "Native American" to align with language used by most Native American people.**

Response - Thank you for your comment and for bringing this to our attention. OHA strives to use language that aligns with community input. The REALD & SOGI standards use the heading "American Indian and Alaska Native" as directed by the agency's Tribal Affairs Liaison. This is a requirement, as collection of information about Native American, Alaska Native, and other identities Indigenous to North and South American is subject to government-to-government agreements with sovereign Tribal Nations.

4. **Public Comment - One comment requested that the race/ethnicity response option "Afro-Latino/a/x/e" should be changed to "Afro-Latino/a." The commenter indicated that the inclusion of the -x and -e suffixes could be confusing or unintelligible to older individuals who hold this identity, particularly those with limited English proficiency.**

Response - Thank you for bringing this potential issue for community members to understand this response option to our attention. We are mindful of the need to ensure the REALD & SOGI survey uses language that is accessible to all community members. This language was requested by members of the community and is intended to honor the diversity of experiences within the community. Removing the -x and -e suffixes from this term would make the survey less inclusive to

non-binary and other gender-nonconforming people who identify as Afro-Latinx or Afro-Latine. We will monitor this response option and work with community members to ensure that it is accessible.

5. **Public Comment - One comment recommended adding several race and ethnicity categories that are common on the West Coast to the categorical race/ethnicity question.**

Response - Thank you for your suggestion on adding race and ethnicity categories that will align with communities on the West Coast. The question asking individuals to select their race/ethnicity (all that apply) includes 63 specific race/ethnicity options, and 9 open-text fields allowing for write-in responses. We created this list in partnership with extensive community input (which included considerations based on Census data for Oregon) and the revised federal OMB data collection standards. It represents a compromise between inclusiveness and conciseness—there are inevitably experiences that are not included in the response options shown. Since these are minimum standards, requestors have the flexibility to include additional response categories that align with the communities they serve. In the future our implementation materials will include a data crosswalk mapping REALD standards to the CDC Race and Ethnicity Code Set, and any response options conforming to this code set will not need to be aggregated prior to submission.

6. **Public Comment - One comment named an issue of compatibility for some Electronic Health Record systems (including Epic, which is widely used across the state). Health records may not have the ability to implement the Primary Race question as required. This question asks individuals who selected more than one race or ethnicity to indicate whether they consider one of the identities they selected to be their primary race/ethnicity and requires the electronic form to populate response options using selections from the previous question.**

Response - Thank you for your comment. We understand that compatibility with Electronic Health Record systems is a common issue. We intend to consider how to address this issue as we build the centralized registry to make it easier to integrate with EHR systems. Meanwhile, the following language has been added to OAR 950-030-0030(3)(b)(C) to address this issue:

> *"If a requestor collects data in an electronic format and uses technology that limits their ability to present a list of racial and ethnic identity categories selected by the individual as stated in (b)(B)(i) of this rule, a requestor may contact the OHA REALD & SOGI Governance Committee to receive guidance on acceptable alternative(s)."*

7. **Public Comment - One commenter indicated that the open-text question asking patients to identify their race/ethnicity often does not get answered, and that patients are frustrated by the perceived redundancy of this question when followed by the question asking them to select from a list of options.**

Response - Thank you for informing us of the experiences that patients are having when filling out the open-text question. REALD & SOGI Standards include free-text responses at the request of community members. Having the option to answer an open-ended question is important to people who do not like labels or have identities that don't fit the available categories. Individuals are not required to answer the open-text questions.

8. **Public Comment - One commenter pointed out an inconsistency in this section; some sections were titled "Standard" while others were titled "Standards".**

Response - Thank you for pointing out this inconsistency. We have addressed this, and section titles have been updated to ensure they are consistent.

Sexual Orientation and Gender Identity

1. **Public Comment - OHA received 5 comments expressing concern that collecting SOGI data from minors creates risk of unintentional disclosure or "outing", especially to parents or guardians. Respondents who brought up this concern recommended that SOGI data not be collected prior to age 18. This recommendation was also made by at least one member of the rulemaking advisory committee (RAC).**

Response - Thank you for your concern about the safety and privacy of minors in disclosing SOGI information. We have been deeply engaged by many partners concerned about this issue. During the development of the SOGI survey, which started in 2018, we received feedback asking us to include SOGI data from minors. This feedback came from gender affirming care providers, advocates for LGBTQ+ youth, and LGBTQ+ youth themselves. These respondents echoed concerns around safety and privacy, and recommended clear communication around who may access minors' data and what controls a minor has over their data as ways of addressing this concern. This recommendation was also made by a majority of members of the RAC.

There is not a functional middle-ground between recommendations in favor of collecting SOGI data from minors and recommendations against collecting SOGI data from minors. However, we can take steps to reduce the risk of unintentional disclosure to parents or guardians. Keeping the concerns brought up by community members and RAC members in mind, OHA will implement the following three plans:

- Advise requestors that in addition to the communication required in ORS 413.164(3), prior to collecting REALD and/or SOGI data from an individual under age 18, requestors should inform the individual of all relevant confidentiality policies and regulations, including who may access the individual's demographic information and whether this information may be disclosed to parents or guardians.
- Make available a patient facing survey tool, so that requestors who do not wish to store SOGI information about minors in their records may have individuals submit their data directly to OHA.

- Convene a learning collaborative where those with experience collecting SOGI data from minors can share their knowledge and experiences navigating safety and confidentiality with other requestors and providers.

2. **Public Comment - One commenter expressed concern about free-text response questions. The commenter indicated that free-text questions should not be required without transparency around how open text field data would be used.**

Response - Thank you for your concern about how individuals' data is being used. Including open-ended questions allows individuals to describe themselves in any way they want, regardless of whether there is a matching check-box available on the form. This is important for people who do not like labels or have identities that don't fit into the available categories. Starting with free-text questions also sets the tone for person-centered, inclusive data collection, sending the message that the language people use to describe themselves is important and valid.

Our team uses tools such as Tableau Prep to maximize our understanding of open text responses and in upcoming implementation materials we will share methods with requestors who wish to understand the agency's practices.

3. **Public Comment - OHA received one comment expressing that asking sexual orientation questions prior to puberty is not age appropriate. Another comment expressed a related concern, that it may be inappropriate to ask SOGI questions prior to age 18 because of the fluidity of experiences and identities at younger ages.**

Response - Thank you for considering the age-appropriateness of SOGI questions. While people of all ages have sexualities and can have sexual orientations, we agree that collecting data about sexual orientation prior to puberty may not be age appropriate. The age at which puberty occurs varies from individual to individual, and we have heard concern from providers about using a one-size-fits-all approach to deciding the age at which sexual orientation questions should be asked.

The fluidity of youth experiences with sexual orientation and gender identity does not make these experiences less valid or suggest that these experiences should not be represented in

demographic data. Youth might experience more changes in their SOGI identities compared to adults.

To address these concerns, we have updated the SOGI standards. They now include three age groups for asking questions. Young children (ages 11 and under) will answer only simplified questions about gender and sex. Adolescents and adults (ages 14 and above) will answer the full set of adult SOGI questions. For minors ages 12 and 13, requestors must choose between the questions for young children or the questions for adults. They should use their professional judgment and follow their organization's policies to decide which questions to use.

4. **Public Comment - OHA received four comments advocating for the addition of categories to various elements of SOGI. These included:**
   - **changing "Asexual" to "Asexual/Ace-spectrum",**
   - **adding "Bigender" as a gender identity option,**
   - **adding "not listed, my gender modality is: _____" to the gender modality question,**
   - **adding "x" or "non-binary" as sex options and expanding options for minors to be in line with guidelines published by other organizations or states.**

Response - We are grateful to the commentors who provided additional input on meaningful categories and response options for SOGI experiences. Given the ongoing national and international conversations about best practices for collecting SOGI data, we have worked to include many of the suggested additions to make the survey more inclusive.

We have made the following decisions:
- Changing "Asexual" to "Asexual/Ace-Spectrum" or "Asexual/Asexual Spectrum": We have adopted this change. The proposed SOGI questions did not properly represent or acknowledge the full spectrum of asexual experiences. This change is a small step to be more inclusive, and we will continue to monitor how asexual experiences can best be represented in SOGI demographic data.
- Adding "Bigender" as a gender identity option: We have adopted this change. We will continue to monitor open text and write-in responses for emerging or missed SOGI categories.
- Adding "x" or "non-binary" as sex options: In creating standards for SOGI categories, we have been careful to use separate language for sex and gender. For example, we use "male" and "female" to describe people's sex and "boy or man" and "girl or woman" to describe people's gender identities. "X" and "non-binary" can be listed on some legal documents in Oregon and other states but are not typically terms used to describe people's anatomical sex. The additional guidance offered in our implementation materials about asking for sex on specific documents provides a better opportunity to represent people whose documents list their sex this way, and therefore we did not adopt this change to the required sex question.
- Adding "not listed, my gender modality is: _____": While we see value in this addition, we chose not to adopt this change for two reasons. First, we are not aware of any terms people use to describe their gender modality beyond the ones presented. Our team will

continue to engage with community feedback and demographic research to monitor whether this changes. Second, the term "gender modality" is a nuanced concept. It is hard to explain in a short tooltip. We are concerned that adding this term to the questionnaire will cause confusion.

- Expanding SOGI questions for minors to be in line with other guidelines: The guidelines mentioned were consulted while initially crafting the questions. However, it is always worthwhile to take a second look. Oregon's Student Health Survey identifies "demi-boy" and "demi-girl" as common gender identities among minors. This finding differs from previous surveys on adults. As a result, we have added the options "demi-boy" and "demi-girl" to the gender identity question for those 14 and older. OHA has also added "both a boy and a girl" as an option to the gender identity question for children under age 12.

As a reminder, the proposed standards are *minimum* standards. Requestors who wish to add additional categories to any of the SOGI questions may do so and can report those to us as "Not listed, specify: ___" write-in responses.

5. **Public Comment - One commenter requested that OHA clarify intention of sex question: is the question intended to collect legal sex information, sex assigned at birth, anatomical sex, or a different concept?**

Response - Thank you for highlighting this. We agree that clarity around the intention of the sex question will be useful. Upcoming implementation resources will explain what is meant by "sex", why it is collected, and how the data can or will be used. We will also provide a short tooltip that requestors may include in electronic forms to clarify what the question means by "sex".

6. **Public Comment - One commentor expressed concern that restricting the visibility of "two-spirit" as a response option to respondents who indicated one or more American Indian and Alaska Native race/ethnicity would exclude Canadian Indigenous peoples as well as anyone who chose not to answer the race/ethnicity question. The commenter requested that OHA remove this restriction.**

Response - Thank you for providing additional community input on the inclusion of "two-spirit" in the survey. Throughout the process of creating SOGI demographic standards, OHA has consistently received requests to link culturally or ethnically specific gender identity and sexual orientation responses to an individual's race/ethnicity responses. OHA heard concern from communities that including "two-spirit" as a response for all individuals would result in incorrect use of the term by people without ties to North American Indigenous cultures.

For individuals with no recorded race/ethnicity information, and for requestors who are unable to link responses from the race/ethnicity questions to this question, the following response option may

be included: "I have a gender identity not listed here that is specific to my ethnicity: _____."

The aggregate category of "American Indian and Alaskan Native" includes the option "Canadian Inuit, Metis or First Nation", so this process will not exclude Canadian Indigenous peoples.

7. **Public Comment - OHA received two comments expressing concern over asking "are you transgender" separately from gender identity. One respondent was concerned that asking the question this way will result in undercounting transgender people when compared to imputing transgender identity using gender identity and sex assigned at birth. Another respondent was concerned that asking "are you transgender" separately could be perceived as "othering" transgender people.**

Response - We appreciate your concern about ensuring that transgender people are accurately represented in REALD & SOGI. Regarding the concern about undercounting, we believe that asking about gender modality separately from gender identity will have the opposite effect. Questions that combine gender identity and gender modality, for example by requiring people to choose between "woman" and "transgender woman" can invalidate transgender identities. Regarding concerns about othering, we have heard from transgender community members and RAC members that the opposite is true.

Imputing gender modality from gender identity and sex assigned at birth may result in under-representation of transgender experiences. However, if a researcher wants to impute gender modality in this way, they may still do so with the proposed SOGI questions, since we also collect gender identity and sex, and we have provided additional guidance for those who want to collect sex assigned at birth.

8. **Public Comment - One comment indicated that including the question "What is your sex" would interrupt the Electronic Health Record System Epic's "Reliable Sex" logic, which uses existing sex fields to guides clinical decision making. The existing fields can't be edited, and introducing an undefined third field may risk clinical error.**

Response - Thank you for bringing forward this potential implementation concern. After reviewing Epic's existing fields, we found that they do not reliably capture intersex experiences. By requiring the sex question, we aim to help analysts identify health inequities affecting intersex people, who are often left out of data collection.

We are creating a provider engagement team to aid in implementation and will work with health systems that rely on Epic or similarly restricted Electronic Health Records to determine how the required sex question can be integrated successfully.

9. **Public Comment - One commenter indicated that requiring different gender questions for children and adults will interfere with continuous record display as the person ages, potentially risking two separate values appearing in an adult's record—their most recently recorded response to the adult question, and their most recently recorded (at age 13 or younger) response to the child gender question. The individual requested that the same question should be used for children and adults but made optional for children.**

Response - Thank you for highlighting a potential complexity for implementing these questions in an electronic health record. It is important to collect information about children's gender identities, and because many of the response options in the adult question are not age-appropriate for young children, the question for children is necessarily different.

We are creating a provider engagement team to aid in implementation and will work with health systems that rely on Electronic Health Records to determine how the required adult and child gender questions can be integrated successfully.

10. **Public Comment - One comment indicated that SOGI questions, particularly sexual orientation questions, collect sensitive information and should not be administered by staff who lack training.**

Response - We appreciate your concern around training and professional development. We agree that requestors' staff should receive appropriate training and supports prior to asking REALD & SOGI questions. Requestors should make sure staff are trained to ask REALD & SOGI questions and are ready to handle a range of responses and reactions when individuals are asked about their sexual orientation and gender identity. We will continue to develop and provide resources to support requestors in training and equipping staff.

11. **Public Comment - One comment requested that OHA remove the language "in any way you prefer" from the open text questions about sexual orientation and gender identity, to avoid implying individuals may have differing definitions of related terms than OHA.**

Response - Thank you for your suggestion. People may define terms and concepts related to sexual orientation and gender identity differently than we do. The language used to describe sexual orientation and gender identity is always changing. People should be able to self-identify as they see fit. This question is intended respect and acknowledge the different experiences and understandings people may have.

12. **Public Comment - One comment requested that OHA change the language "What is your gender?" to "Which of these selections best describe your gender? Select all that apply." The comment made the same request for the question "What is your sexual orientation?"**

Response - We appreciate the nuance in this suggestion. The suggested wording accomplishes a similar goal, but we have kept the existing question language. We believe it is simpler and easier to understand, which helps with interpretation, translation, and accessibility.

13. **Public Comment - One commenter suggested either removing the definition of "straight" from the response option for the sexual orientation question, which read "Straight (attracted mainly to or only to other gender(s) or sex(es)".**

Response - Thank you for this insight. This highlighted that "straight" was the only option in the REALD & SOGI questionnaire with an in-text definition. We have removed the definition and replaced the category with "straight or heterosexual." A definition for this term will be included in upcoming implementation materials, including suggested tooltips to be used with electronic forms.

Appendix A

Public comments provided by the following:

Andi Easton, Government Relations Director, Samaritan Health Systems

Antoinette Awuakye, JD, Cambia Health Solutions

Betsy Boyd-Flynn, Executive Director and CEO, Oregon Academy of Family Physicians

Brian Frank, MD, External Affairs Committee, Oregon Academy of Family Physicians

Cat Livingston, MD, Health Share of Oregon

Chris Keating, Washington County

Deborah Rumsey, Executive Director, Children's Health Alliance

Julia Przedworski, PhD

Julie Scholz, Executive Director, Oregon Pediatric Society

Katie Harris, Hospital Association of Oregon

Lauren Jackson, OPMA, OHA, Office of Data Strategy and Operations

Mark Bonanno, JD, MPH, Oregon Medical Association

Nick Gilla, Native American Youth and Family Center (NAYA)

R.J. Gillespie, MD, MHPE, FAAP, Pediatrician at the Children's Clinic

Resa Bradeen, MD, Chief Medical Officer, Children's Health Alliance

Ricki Pelta, Senior Counsel, American Council of Life Insurers

Tae-Sun Kim, PhD, Vice President and Chief Diversity Officer, Legacy Health System

Tara Harrison, JD, Government Affairs Director, Providence Health Plan

Sonney Sapra, Senior VP, CIO, Samaritan Health Services

Kelly Kaiser, Senior Vice President, CAO, Samaritan Health Services

Brent Godek, MD, Vice President, Samaritan Health Services

Christina Milano, MD – Medical Director of the Transgender Health Program, OHSU

Amy Penkin – Clinical Program Manager of the Transgender Health Program, OHSU

Donn Spight, MD – Vice President of Health Equity, OHSU

Kat Phillips – Senior Director of Health Equity, OHSU

Johanna Warren, MD – Senior Associate CMO of Ambulatory Practice, OHSU

Brian Park, MD – Medical Director of Health Equity, OHSU

Kristi Cushman – Director of Patient Access, OHSU

Stephanie Schmidt – Senior Director of Ambulatory Operations, OHSU

Melissa Preciso-Temple – Interim Director of Ambulatory Services, OHSU

Banning Hendricks – Director of Patient Experience, OHSU

Melissa Monner – Director of Patient Relations, OHSU

Basilia Basin – Assistant Director of Patient Relations, OHSU

Anais Keenon – ADA Coordinator, OHSU

Armando Jimenez – Director of Language Services, OHSU

Wade Anderson – Director of Finance and Operation Analytics, OHSU

Rachel Navarro – Manager of Epic Ambulatory Applications, OHSU

Bridget Schrader – Manager of Epic Shared Services, OHSU

Kathy Quintos – Manager of Epic IT Applications, OHSU

Kristen Sharp – Epic Clinical Informatics Specialist, OHSU

Lunette Lott – Epic Senior Clinical Informatics Specialist, OHSU

Jennifer Craft – Epic Senior Clinical Informatics Specialist, OHSU

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