Equity and Inclusion Division

OHA and ODHS REALD and SOGI Legislative Report 2024













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EXECUTIVE SUMMARY

In 2013, the Oregon Legislature passed HB 2134 (ORS 413.161). The law directed the Oregon Health Authority (OHA) and the Oregon Department of Human Services (ODHS) to collaborate in standardizing and improving how race, ethnicity, spoken and written language, and disability (REALD) demographics are collected. This effort arose from the need to address inconsistent and insufficient data collection standards used to collect these variables across ODHS and OHA programs and activities. Collecting consistent standardized demographic information helps analysts better identify inequities in services and health outcomes. The REALD data collection standards were developed and were codified in Oregon Administrative Rules in 2014 after a thorough process of consultation with external partners and researchers.

To receive a hard copy of this report, email: OHAREALD.Questions@odhsoha.oregon.gov

This report will also be available at: https://www.oregon.gov/oha/EI/Pages/REALD.aspx

Document accessibility: For individuals with disabilities or individuals who speak a language other than English, OHA can provide information in alternate formats such as translations, large print, or braille. Email OHAREALD.Questions@odhsoha.oregon.gov or call 971-673-3390. We accept all relay calls.

Introduction

The first REALD legislative report in 2014 provided a baseline assessment of ODHS and OHA data systems with respect to the REALD standards as required by ORS 413.161 (HB 2134 passed in 2013). In 2016, a report was submitted with the request to Ways and Means for 5 FTE to support implementation of REALD across OHA (1), ODHS (3) and OIS (1). Subsequent reports (2018, 2020) have reported on the progress of implementing the REALD data collection standards.

The REALD data collection standards were first codified in the OARs in 2014 and have since been updated twice; once in 2020 in response to legislation (HB 4214) which required providers ordering COVID-19 testing to submit REALD data to OHA, and again in 2024 in response to new requirements to add sexual orientation and gender identity (SOGI) (ORS 413.163; HB 3159 which passed in 2021). In addition to requiring SOGI data collection standards to be codified in the OARs, HB 3159 requires OHA to develop a grant program to support data collection by community health organizations and community-based groups with demonstrated experience serving communities most impacted by health inequities (ORS 413.166).

ORS 413.163 also included a requirement to develop a data Registry to receive REALD & SOGI data from providers, insurers, and coordinated care organizations (CCOs) who will be required to submit REALD and SOGI data annually for all patients/members to OHA once the Registry is built (ORS 413.164). Along with the Registry is a need for a Repository to store and process the REALD & SOGI data to maximize data quality. In 2022, OHA submitted a policy option package which ultimately allocated funding and resources to support building the integrated Registry/Repository data system.

Purpose

This report provides a description of the standards, progress, and challenges in implementing the standards across all data systems as well as plans for addressing identified challenges as required by ORS 413.161, ORS 413.163 and ORS 413.164 from July 2022 through June 2024.

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OHA & ODHS Summary

Monitoring Compliance

Overall, REALD compliance among OHA and ODHS data systems has improved over the last ten years of implementation, especially among those systems the agency has direct control over in terms of data collection. We expect that once the Registry is built, compliance will increase significantly for those systems dependent on data from health providers or insurers as these systems will be able to receive REALD & SOGI data from the Repository. The REALD & SOGI team from OHA, Equity & Inclusion (E&I) Division and ODHS continues to work closely with colleagues across OHA and ODHS to share the value of REALD; implement REALD data collection standards in existing and newly developed data systems; and make progress on OHA's strategic goal of eliminating health inequities by 2030.

Updates to the Integrated Eligibility (ONE-IE) System

The ONE-IE system has undergone a series of changes since 2017 when the REALD data standards were first added. OHA and ODHS collaborated on the updates for the ONE-IE in 2021-22 which ensured compliance with the 2020 REALD standards. We are currently in the process of updating the ONE-IE system to ensure alignment with 2024 standards; this is a lengthy process and will be completed in March 2025.

REALD & SOGI Data Governance Committee

The first REALD Data Governance Committee was formed in 2018 in OHA. Since then, the Governance Committee has become an interagency (OHA & ODHS) REALD & SOGI Data Governance Committee (DGC). This advisory group, which comprises data systems owners and their data stewards, meets monthly and will support the implementation of REALD &SOGI standards and approve data requests.

ODHS Summary

Implementation of REALD data standards in ODHS has been moving at a slow but steady pace. Among the most significant challenges facing accelerated implementation of REALD data standards (and the soon to be approved SOGI demographic additions) are limited staffing, insufficient funds for system improvements and the need to align with a larger agency-wide vision for data governance and enhancements.

Forward motion on the ODHS REALD Implementation plan has primarily focused on developing communication, training, structural supports, and initial reporting efforts. The team has also focused on building relationships among OHA and ODHS staff who gather, analyze, and report using REALD data. As a result of these efforts, ORKids, CAM and the new ODDS Case Management systems have built REALD standards into their systems. These are among the largest data systems in ODHS, along with the ONE-IE system, and will cover most Oregonians who interact with ODHS service programs.

OHA Summary

Like ODHS, OHA's progress in implementing REALD data collection standards has been slow. However, COVIDera legislation requiring providers ordering COVID-19 testing to submit REALD data to OHA has quickened this pace (HB 4212; 2020-2023). The success of this legislation became the impetus for HB 3159, passed in 2021,

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which expanded the requirement to all providers, insurers and CCOs to submit not just REALD but also SOGI data to OHA once the centralized Registry is built (to receive the data). HB 3159 was accompanied by an investment that significantly strengthened OHA's own infrastructure and staffing to do this work, with dedicated REALD & SOGI staffing in the E&I Division, Office of Information Services, Health Policy and Analytics Division and Health Systems Division.

STATUS REPORT ON STANDARDS, PROGRESS, CHALLENGES

OHA & ODHS Status, Progress, Challenges

Updating the Demographic Data Collection Standards

Since 2014, the Equity and Inclusion Division (E&I) of OHA, in collaboration with ODHS, has continuously improved the REALD data collection standards (Chapter 950, Division 30 of the Oregon Administrative Rules). Table 1 provides a summary of changes made to the data collection standards codified in the OARs since 2014. Changes to the REALD data collection standards in 2020 were made in response to HB 4212 which required providers ordering COVID-19 testing to submit REALD data to OHA. Some of these changes came from better understanding, for example, the effectiveness of the language questions. Other changes came from identifying a gap in the disability questions, and in response to a need to better identify people with intellectual and developmental disabilities who were more impacted by COVID-19. These changes were informed by community engagement and data quality reports (see appendix A for an at-a-glance view of the 2020 template).

While the REALD coordinator in OHA convened a SOGI Workgroup in 2018 to develop draft SOGI standards prior to the pandemic, there was insufficient capacity to convene a rulemaking advisory committee to finalize the SOGI standards and refine the REALD standards until November of 2023. Between 2018 and 2023, OHA gathered extensive feedback from over 400 community members, subject matter experts, and lived experience experts statewide. OHA also commissioned research on pediatric SOGI data collection. These research and community engagement processes gathered insight from gender-affirming care providers, advocates for LGBTQ+ minors, and LGBTQ+ minors themselves.

To develop the 2024 standards, community partners with subject matter expertise in one or more REALD & SOGI topic areas were consulted through a rulemaking advisory committee which met four times. In addition to adding SOGI, there were updates made to improve REALD data collection. All the standards are designed to roll up to other federal reporting requirements. OHA has developed several crosswalks to aid partners and analysts in meeting the different federal reporting standards. This includes the recently updated United States Office of Management and Budget (OMB) standards for race/ethnicity. The adoption of the new rules went into effect July 2, 2024 (see Appendix B for an at glance view of the 2024 template).

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Table 1. Summary of Changes to REALD & SOGI Data Collection Standards

		2014 (Baseline)	2020	2024
Race /	Open Text	Yes	No change	No change
Ethnicity	# of Identities	34	Added 5 (total 39)	Added 33 to accommodate OMB updated changes and per RAC (total 74, including 7 free text fields)
	Primary Race	Yes	Revised for clarity	No change except for minor editing
Language	Languages Preferred	Spoken, Written	Added Home Language	Added question about home language to help create skip patterns
	Interpreter Needs	Two questions – need Interpreter; need Sign Language Interpreter	Revised interpreter need questions for clarity (combining interpreter and sign language need and added xx options for types of interpreters)	Added 2 additional types of interpreters
	Other Language Access Needs	Alternative Format	Dropped alternate format question.	Added a new question about captioning and assistive device needs with 5 number of response options
Disability	# of questions (and # of age acquired questions)	6 ACS and 1 BRFSS question with 6 age acquired questions	Dropped BRFSS; added 3 questions (Communication, Learning, Mental Health) & 3 age acquired follow-up questions.	No change
	Open Text	No	No	Added
	Accommodation Needs	No	No	Added
Sex	Sex Question	No	No	Added
Gender	Open Text	No	No	Added
Identity & Gender Modality	# of identities	No	No	Added 15 response options
Wiodanty	Youth Question	No	No	Added
Sexual Orientation	Open Text	No	No	Added
Orientation	Number of identities	No	No	Added 13 response options

Note. ACS = American Community Survey (Census); BRFSS = Behavioral Risk Factor Surveillance System.

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Updates to the Integrated Eligibility (ONE-IE) System

The ONE-IE system has undergone a series of changes since 2017 when REALD was first added. OHA & ODHS collaborated on the updates for the ONE-IE in 2021-22 which ensured compliance with the 2020 REALD standards and included the gender identity standards as well. We are currently in the process of informing the changes to ONE-IE to be in alignment with the 2024 standards which is expected to be completed in March 2025. This is a lengthy process involving a series of design sessions to ensure the updates are done with fidelity to the standards. See Table 2 for a summary of changes by ONE-IE domain.

Table 21: REALD updates by relevant ONE-IE domain

ONE Online App	OHP Paper App	MMIS ^a Database	834 EDI ^b to CCOs
June 2017 (REALD) April 2022 (REALD + Gender Identity) March 2025- REALD & SOGI updates for 2024 standards	January 2020 (REALD) Fall 2022 (REALD + Gender Identity) TBD: Next updates (for 2024 standards)	June 2017 (REALD) Fall 2022 (REALD) TBD: Next updates (for 2024 standards)	May 2018 (REALD) Fall 2022 (REALD) TBD: Next updates (for 2024 standards)

^a Medicaid Management Information System; ^b Electronic Data Interchange.

Monitoring Compliance

The REALD & SOGI team in OHA E&I currently tracks compliance of 88 datasets across OHA and ODHS. Sixteen (18.2%) of these datasets are not applicable to ORS 413.161 because they are linked databases using information from other or multiple sources (downstream), inactive, or are currently exempt from implementing REALD & SOGI (See Appendix C for details). See Table 3 for some examples of non-applicable data systems and the reason why not applicable.

Table 3: Example of non-applicable data systems

Name of Data Source	Reason for non-applicability
DAS/HR - Workday	Workday applies to all state agencies
Integrated Client System (ICS)	ICS collects data from other systems (linked)
DHS Volunteer Database	Inactive
Health Prof. Shortage Areas & Medically Underserved Areas	Federal data system not able to be modified
Decision Support/Surveillance & Utilization Review System	Collection of tables from another data system

Of the remaining applicable data systems, 15 are in compliance (21,8% of 72) with ORS 413.161 and most are internal systems where there is greater control in implementation and compliance (see Table 4; Appendix D). Examples of internal data sets with high control include the following:

IE/ONE

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¹ ONE compliance with REALD is multifaceted due to the downstream effect of changes in the ONE system. The ONE electronic application is the first process to undergo adjustments via change requests. Two change requests have been facilitated since the start of REALD in 2014 (in 2017 and in 2022). Following the ONE electronic system, the ONE Oregon Health Plan (OHP) paper application also needs to be adjusted. The Medicaid Management Information System (MMIS) is a separate data-system that is a subset of the ONE population for OHP recipients. The 834 file to CCOs is a daily update for CCOs on current enrollment by CCO.

- Centralized Abuse Management
- SACU (Stabilization and Crisis Unit)
- SSP Well-Being Survey
- Regional Health Equity Coalition (RHEC) Membership Application
- Consumer Assessment of Healthcare Providers & Systems Survey (CAHPS)
- Health Evidence Review Committee Membership Application
- Mental Health Statistics Improvement Program Survey (MHSIP)
- OR Health Insurance Survey (OHIS)

Many of the data systems not in compliance will eventually be in compliance when the Registry goes live (estimated 2026/27); for this reason, the level of control is considered medium. These data systems (n = 29) are reliant on data from providers and insurers. Examples of external data systems reliant on data from providers and or insurers include the following:

- Pregnancy Risk Assessment Monitoring System (PRAMS)
- Newborn Screening
- Electronic Survey System for Early Notification of Community-Based Epidemics (ESSENCE)
- Oregon State Cancer Registry (OSCAR)
- Pesticide Exposure Safety & Tracking (PEST)
- Early Hearing Detection & Intervention (EHDI)
- OVERS Birth Certificate
- Fetal Death

Finally, there are 5 applicable data systems that rely on other external data sources, and these will be hardest to bring into compliance as the data is not collected by providers or insurers. These five include the following:

- Marriage Certificates
- Divorce
- Oregon Registered Domestic Partnership
- Dissolution of Domestic Partnership
- 211 Info

The relationship between type of data system (source type) and compliance is largely dependent on the level of control OHA/ODHS staff have on changes to data elements collected as well as how the data is collected. Level of control, in this context, is not dependent on resources or funding availability. Most of the compliant data systems are a high level of control. Medium level of control refers to those systems that ultimately will be in compliance once the HB 3159 Registry/Repository system goes live (expected 2026/27) (Table 4).

Table 4: Compliance Status of Applicable Data Systems by Data Source Type

Level of Control	Compliant		Partial o	r Planned	Inco	mpliant	Total		
Level of Control	No.	%	No.	%	No.	%	No.	%	
Low	0	0.0	0	0	5	12.2	5	6.9	
Medium	2	13.3	4	25	23	56.1	29	40.3	
High	13	86.7	12	75	13	31.7	38	52.8	
Total	15	100	16	100	41	100	72	100	

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Table 5 provides greater insight on the relationship between source type and compliance status. Many of the data systems not in compliance (23 of 41) are those reliant on data from providers and insurers (medium control). We anticipate that these systems ultimately will be in compliance once the HB 3159 Registry system goes live.

Table 5: Compliance Status of Applicable Data Systems by Data Source Type

Source Type	Compliant		Partial or Planned		Incompliant		Total	
Source Type	No.	%	No.	%	No.	%	No.	%
External-Other	0	0	0	0	5	12.2	5	6.9
External-Providers/Insurers	2	13.3	4	25.0	23	56.1	29	40.3
Internal Only Database	5	33.3	8	50.0	11	26.8	24	33.3
Internal: Membership/Committee	4	26.7	0	0.0	0	0.0	4	5.6
Internal: Survey	4	26.7	4	25.0	2	4.9	10	13.9
Total	15	100	16	100	41	100	72	100

Public Health has the most systems not in compliance (31 of 41) (Table 6); however, many of these systems will be in compliance once the HB 3159 Registry/Repository system is implemented (Table 7).

Table 6: Compliance Status by Agency / Divisions

Agency / Division	Con	Compliant		Partial or Planned		Incompliant		otal
Agency / Division	No.	%	No.	%	No.	%	No.	%
Shared/Many	1	6.7	0	0.0	2	4.9	3	4.2
OR Dept of Human Services	3	20	5	31.3	5	12.2	13	18.1
Equity & Inclusion	2	13.3	1	6.3	1	2.4	4	5.6
Health Policy & Analytics	5	33.3	2	12.5	2	4.9	9	12.5
Health Services	0	0	2	12.5	0	0	2	2.8
Oregon State Hospital	1	6.7	0	0.0	0	0	1	1.4
Public Health	3	20	6	37.5	31	75.6	40	55.6
Total	15	100	16	100	41	100	72	100

Table 7: Level of Control by Agency / Divisions

Agency / Division	Low C	Low Control		Medium Control		High Control		otal
Agency / Division	No.	%	No.	%	No.	%	No.	%
Shared/Many	1	20	0	0	2	5.3	3	4.2
OR Dept of Human Services	0	0	0	0	13	34.2	13	18.1
Equity & Inclusion	0	0	0	0	4	10.5	4	5.6
Health Policy & Analytics	0	0	2	6.9	7	18.4	9	12.5
Health Services	0	0	2	6.9	0	0.0	2	2.8
Oregon State Hospital	0	0	0	0	1	2.6	1	1.4
Public Health	4	80	25	86.2	11	28.9	40	55.6
Total	5	100	29	100	38	100	72	100

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The REALD & SOGI team continues to work closely with our colleagues across OHA and ODHS to share the value of REALD, implement REALD data collection standards in existing and newly developed data systems and facilitate progress on OHA's strategic goal of eliminating health inequities by 2030.

REALD & SOGI Data Governance Committee

The current REALD & SOGI Data Governance Committee (DGC) comprising representatives of data systems and data stewards from OHA and ODHS divisions and programs helps to strengthen interagency communication and partnerships about data standards and provides a forum for discussing implementation-related issues, modifications, and technical assistance. We are working together now to explore developing a joint interagency REALD & SOGI implementation and reporting policy.

ODHS Status, Progress, Challenges

Overview of successes, barriers and resources needed

The ODHS REALD Implementation Plan prioritizes four areas to support the integration of REALD into agency systems and surveys: Communication, Implementation Structures, Training and Reporting.

Communication: Recognizing that prior to 2021, many ODHS staff did not know about or understand the REALD & SOGI demographic standards, communication and training have been high priorities over the past several years. Five REALD & SOGI tools have been developed, regularly utilized, and updated over the past two years. These include a bi-monthly Newsflash, FAQ page, resource page, email listserv and a regularly updated ODHS REALD & SOGI website. By the end of 2023, these tools were reaching an estimated 250+ staff each month.

Implementation Structures: Building off the partnership with OHA, ODHS has appointed several members to the REALD & SOGI Data Governance Committee. ODHS is also in the process of standing up an internal REALD Implementation Team representing each agency program area. Following the codification of OHA's revised rules in the summer of 2024, ODHS will begin the process of revising its own rules and policy.

Training: A series of learning labs began in 2023 to help staff understand the equity importance of disaggregated data, ask the REALD questions in culturally respectful ways, and explore the deeper principles of Data Equity and Data Justice Concepts. These learning labs will increase in 2024-25 and be coupled with the 1-on-1 consultation with every program unit across the agency.

Reporting: The ODHS REALD staff remain in close communication with the Office of Research, Reporting, Analysis and Implementation (ORRAI) as well as the E&I REALD & SOGI Section overseeing the development of the Integrated REALD & SOGI Data Registry/Repository. As REALD and SOGI data collection becomes more robust and staff grow to understand the value of disaggregated data, conversations around how to best report and utilize REALD & SOGI data will become more a norm. Reporting will become a growing priority in the years ahead.

The most significant barriers to deeper integration of REALD & SOGI data standards are limited staffing, insufficient funds for system improvements, and the need to align with a larger agency-wide vision for data governance and enhancements.

ODHS REALD & SOGI Staff – Since the inception of the REALD project in 2013, ODHS has
had limited FTE to support an agency-wide effort to integrate REALD (and now SOGI)
disaggregated standards into more than 100 diverse downstream systems, surveys, and forms.
The project is making best use of existing data equity positions in various programs, but agency-

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- wide compliance and support across 6 programs and more than 10,000 staff is challenging with limited FTE. Ongoing efforts to advocate for additional ODHS REALD & SOGI staff will continue.
- Funds for System Improvements REALD & SOGI demographic standard implementation requires significant program commitment of staff time and funding for IT system change. Currently, most programs work to integrate REALD & SOGI mandates into existing upgrades but find the additional requirements challenging to meet within existing budgets. Specifically earmarked funds for additional staff and financial support for program improvements related to REALD & SOGI improvements would address these challenges.
- Agency-wide vision and support ODHS is working to improve its overall data governance
 and enhancement plans. Given the REALD & SOGI project's reliance on agency-wide IT and
 information infrastructure, improved communication, training, and staffing at the agency-level
 would pave the way for more efficient and effective implementation and use of REALD & SOGI
 disaggregated data standards.

OHA Status, Progress, Challenges

Staffing

Due to the resources allocated in 2021 with the passage of HB 3159, a new REALD & SOGI Section was created within the Equity & Inclusion Division of OHA. A subsequent policy option package approved in 2023 secured additional positions to support the implementation of ORS 413.163. However, the Section has been understaffed. due to challenges in gaining approvals by the Department of Administrative Services (DAS) for the positions as they were initially budgeted for and classified. This resulted in a delay in many of the implementation activities, such as convening the rulemaking advisory committee to finalize the SOGI data collection standards and developing the grant program as required by ORS 413.166. As of June 30, 2024, 19 of 32 FTE positions have been filled; we anticipate being fully staffed by October 1st, 2024.

Figure 1 provides a visual depiction of the key functions this team fills to achieve REALD & SOGI implementation and maximize OHA's ability to identify and address inequities using the REALD & SOGI data collection standards.



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Governance

Community engagement and shared leadership

OHA's REALD & SOGI Section is currently developing a Community Workgroup (the Workgroup) for communities most impacted by health inequities to provide feedback and guidance to OHA on the collection and use of REALD & SOGI data. This work has been supported by a contractor, Public Solutions Northwest since the Fall of 2023. The contractor held four Q & A sessions regarding the workgroup, with another pending on July 17th focusing on Disabilities communities' recruitment specifically. The Community Engagement team was instrumental in recruitment and selecting the nominees for the workgroup. The initial membership of the Workgroup was selected in May 2024. Recruitment for an additional four members from Eastern Oregon and Disabilities Communities is ongoing. The first meeting will be July 18th. This Workgroup will be one component of a consistent feedback loop between the OHA REALD & SOGI Section and communities to continuously improve OHA's approach to supporting communities' use of REALD & SOGI data to do data justice. We anticipate that the legislatively mandated REALD & SOGI Advisory Committee will emerge from this work.

Enterprise REALD & SOGI Data Standards for Systems

Effective implementation and use of REALD & SOGI data to identify and address inequities systems-wide require standardized data tools and practices. Accordingly, OHA has developed several enterprise-wide tools including the REALD & SOGI data dictionary, a language list comprising over 7,000 international standards language (ISO codes) with user friendly smart filtering, and several methodological code books to support REALD & SOGI Repository use. These tools and their guidance documents not only inform the enterprise-wide use of REALD & SOGI data but reinforce standardization in how the data is used to inform the development of metrics, analysis, measurement, and interpretation to inform policy and programmatic decision making. Since their implementation, there is measurable evidence to suggest the tools have helped to improve the implementation and use of REALD & SOGI data enterprise wide. We will be creating a web page with these tools so that others can access more easily.

Integrated REALD & SOGI Registry/Repository Data System Overview

The build of a demographic population-based Integrated Registry and Repository data system, consisting of all individuals receiving care from licensed providers and insurers providing care in Oregon, will reduce cost incurred with siloed data systems and incomplete data, reduce time-to-value for measure and analyses on health outcomes for Medicaid clients, increase interoperability, and drive innovation. This will then extend OHA's ability to identify and address inequities, including by insurance source (e.g., Medicaid vs Medicare vs Private using for instance All Payers All Claims (APAC) data). Once the Registry is built, the data from the Repository will also be available to 30+ data systems, the majority of which are public health surveillance systems, such as the Cancer Registry and the Oregon Acute Care Hospital Inpatient Discharge data system.) OHA will be able to do more to identify and address inequities for Medicaid members who are also present in the other surveillance data systems. For example, with the enrichment of the Cancer Registry data, OHA and partners will be able to better identify and address inequities in cancer screenings by race, ethnicity, language, disability, gender identity and sexual orientation. Three system components are described below listed in order of development (phases).

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Phase 1 – Patient Facing Survey Tool

The Patient Facing Survey Tool (PFST) is a secure, web-based form that allows individuals to enter their REALD & SOGI information to facilitate easy automatic reporting to the OHA. This was created during the pandemic to offer providers the option to use a customized REALD & SOGI survey link or a QR code (with their information embedded in the QR code). The PFST allows patients to use the link or QR code to complete the REALD questions. Initially developed by an external vendor during the pandemic, the PFST has been transitioned to the Office of Information Services (OIS). Additional work will be done on the PFST to integrate with the Registry in the future.

Phase 2 – Repository

The REALD & SOGI Repository was implemented following <u>detailed assessment</u> of REALD data quality in Medicaid Management & Information System (MMIS) / Decision Support & Surveillance Utilization Review System (DSSURS) conducted in 2018; we found the MMIS system inadequate to fully maximize the data quality of REALD & SOGI data. Thus, the Repository began development in 2022 in the E&I Division to maximize the use of REALD data, drawing from the ONE eligibility system as well as high quality REALD data from other internal sources (Birth Certificate and Acute and Communicable Disease data (e.g., COVID)). Additionally, OHA is now ingesting data from medical providers via CSV standard formats, and directly from provider offices via the PFST which utilizes an embedded QR code for flexible data collection. Currently, over 90% of the records in the Repository include demographic data from Medicaid members. There are plans to receive REALD & SOGI data directly from All Payers All Claims (APAC) insurers serving over 5000 members beginning in early 2025 as well as CCOs.

As a result of ingesting and processing data from REALD compliant data sources, the Repository can now share more complete and quality REALD & SOGI data as appropriate and approved via governance. Due to the approach, we take in maximizing data quality and data completeness among all data sources in the Repository as well as leveraging multiple sources of data for the same person, we are able to significantly reduce non-responses. For example, in a data pull on July 8th, 2024, with Medicaid members with additional data sources, we found that the percent of non-responses for primary race/ethnicity decreased from 22.7% to 5.8% (Table 8).

Due to increased systems-wide confidence in utilizing quality REALD & SOGI data from the Repository, E&I began sharing data from the Repository with analysts primarily working with the Medicaid data in January of 2023, and provided extensive training to support internal analysts' understanding and use of the REALD & SOGI data from the Repository (see Table 9 below). Curated extracts of the Repository data have also been shared with multiple internal and external partners, including program staff and research analysts working across ODHS and OHA programs. Projects that utilized Repository data for reporting and visualizations include the following:

- 2017-2022 1115 Waiver Summative Report submitted to CMS
- CCO Metrics Equity Centered Benchmarking Data Feasibility Report
- CCO performance metrics dashboard visualizations (2021, 2022, 2023 coming soon)
- Evaluation of the Effectiveness of Health Care Provider Incentive Programs in Oregon
- Medicaid member dashboard visualizations
- Systems of Care dashboard
- The Healthy Oregon People Report

The Repository data was also used for the 2024 legislative bill analyses, as well as other research related to OHA's 2030 goal to identify and eliminate health inequities. The development of the Repository represents a significant

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milestone in our work to ensure the systems-wide use of more complete and quality demographic data to inform policy and programmatic decisions.

In September 2023, OHA started sharing bi-monthly data extracts from the Repository to CCO/Fee for service (FFS) contractors. With this data, CCO and FFS delivery contractors are better able to use more complete and quality patient and member demographic data to deliver culturally appropriate and patient and family-centered care to the state's Medicaid and FFS members. In advance of the data sharing with CCO/FFS contractors, staff from the REALD & SOGI section in the E&I Division worked with data analytics and informatics representatives from CCOs to evaluate their data needs and appropriate mechanisms for sharing the data. Our team then worked with our agency partners to design, test, and implement a system to share REALD & SOGI demographic data. We also provided extensive training to support CCOs' understanding and use of the REALD & SOGI data for identifying and addressing health inequities in their member populations (see Table 9).

Further enhancements are in progress to improve the accessibility, efficiency, and security of the data. To align with the state's "cloud forward policy" we are working on migrating the REALD & SOGI Repository system from its current physical server located in the state data center to a cloud environment. The specific benefits of this migration include increased processing speed of ingesting and outputting data, offering better scalability to ensure the Repository can meet increasing demands for REALD & SOGI data, leveraging machine learning and artificial intelligence to improve data quality. In addition, the cloud migration provides better options for disaster recovery, ensuring that in the event of an emergency, the Repository can remain functioning and continue to provide data. The cloud migration will also bring the Repository into contact with advanced technological opportunities not available from the physical server location. Other enhancements planned include the following:

- Development of a data request portal that will provide quicker and more robust access to data
 users and requesters. As demand for Repository data has increased, we have identified the
 need to streamline and automate this process to ensure that data requests can be handled
 quickly and efficiently, including governance/approval process, extract building, and data
 transfer.
- Development of a data analytics and reporting portal which will provide analysts with access
 to preconfigured templates and reports about Repository data, ensuring better standardization
 of reporting and giving non-technical users the opportunity to have a report, visualization, or
 dashboard of their choice developed based on one or more provided templates.

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Table 8: REALD Race/Ethnicity Data Quality – Before/After in a Mixed Sample

	Befo	Before		After		Difference (Final - Stage2)	
	No.	%	No.	%	No.	%	
Missing	89,770	14.91	26,975	4.48	-62,795	-10.4	
Decline	36,579	6.07	6,838	1.14	-29,741	-4.9	
Unknown	10,336	1.72	1,113	0.18	-9,223	-1.5	
Total Non-Response	136,685	22.7	34,926	5.8	-101,759	-16.9	
American Indian	12,790	2.12	19,544	3.25	6,754	1.1	
Alaska Native	680	0.11	1,554	0.26	874	0.2	
Canadian Inuit/Metis/First Nation	44	0.01	118	0.02	74	0.0	
Indigenous Mex/Cen/So American	1,618	0.27	3,240	0.54	1.622	0.3	
Asian Indian	711	0.12	1,674	0.28	963	0.0	
Cambodian	106	0.02	263	0.20	157	0.0	
Chinese	1,731	0.29	4,164	0.69	2,433	0.4	
Communities of Myanmar	15	0.23	657	0.11	642	0.1	
Filipino/a	1,662	0.28	3,078	0.11	1,416	0.1	
Hmong	189	0.20	420	0.07	231	0.2	
Japanese	518	0.03	1,590	0.07	1,072	0.0	
Korean	765	0.03	1,883	0.20	1,118	0.2	
Laotian	152	0.13	493	0.08	341	0.2	
South Asian	276	0.05	593	0.00	317	0.1	
Vietnamese	2,314	0.38	4,423	0.73	2,109	0.1	
Other Asian	3,707	0.62	14,826	2.46	11,119	1.8	
African American	10,260	1.7	14,006	2.33	3,746	0.6	
Afro-Caribbean	184	0.03	713	0.12	529	0.0	
Ethiopian	199	0.03	417	0.12	218	0.0	
Somali	132	0.03	477	0.07	345	0.0	
Other African	1,367	0.02	3,885	0.65	2,518	0.1	
Other Black	4,578	0.76	4,941	0.82	363	0.1	
Latinx Mexican	22,606	3.75	57,209	9.5	34,603	5.8	
Latinx Cen American	1,656	0.28	4,974	0.83	3,318	0.6	
Latinx Sou American	599	0.1	2,423	0.4	1,824	0.3	
Other Latinx	34,685	5.76	41,328	6.86	6,643	1.1	
Middle Eastern	1,245	0.21	3,052	0.51	1,807	0.3	
North African	123	0.02	741	0.12	618	0.3	
CHamoru (Chamorro)	244	0.02	511	0.08	267	0.0	
Communities of Micronesian Region	1,080	0.18	1,348	0.00	268	0.0	
Marshallese	237	0.10	306	0.05	69	0.0	
Samoan	438	0.04	762	0.03	324	0.0	
Native Hawaiian	687	0.07	1,671	0.13	984	0.1	
Other Pacific Islander	2,247	0.11	3,122	0.52	875	0.2	
Eastern European	8,151	1.35	12,674	2.1	4,523	0.8	
Slavic	1,903	0.32	3,616	0.6	1,713	0.3	
Western European	33,754	5.61	51,002	8.47	17,248	2.9	
Other White	269,051	44.68	284,197	47.2	15,146	2.5	
Multi (not otherwise specified)	39,553	6.57	11892	1.98	-27,661	-4.6	
Other race	3,216	0.53	3,445	0.57	229	0.0	
Total	602,158	100	602,158	100	0	0.0	

Note. The sample was based on Medicaid members who had at least one other data source in the repository.

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Phase 3 – Registry & Integrations

Phase 3 includes development of the REALD & SOGI Registry which will be the primary hub for data intake and will provide varied mechanisms for inputs including from electronic health records (EHR) systems, from individuals taking an online survey with a QR code shared by the provider or insurers, and directly from individuals via an online portal/mobile application. The team has made significant progress on the planning and designing of the HB 3159 Registry which is the 'front door' for data submissions from providers, insurers and CCOs.

Staff from the REALD & SOGI section partnered with internal OHA and ODHS divisions to develop functional and non-functional requirements of the Registry to inform design and future implementation. The partnership team relied on multiple strategies to develop and refine Registry use cases, gather and refine requirements, systems design and their integration points. The partnership helped to create over 20 separate workstreams focused on identifying and addressing issues related to specific components of the Registry and be responsive and reactive to risks identified by the different workstreams. For example, one of the workstreams focused on identifying specific needs from downstream data users across ODHS and OHA, this included over 10 separate meetings between project staff, program specific data system owners; the deployment of a targeted survey to data system owners to identify their needs, desires, and challenges related to sending data to the Registry and or receiving data from Repository. The cadence of regularly scheduled meetings, full day in person sessions, and targeted workstreams have helped the project team to develop detailed diagrams that incorporate feedback and guidance from partners across both state agencies.

Based on our learnings from the planning and preparatory work done by the partnership, we are now exploring more than one path for developing the HB 3159 Registry; the standard request for procurement process (RFP) and an internal Registry development through partnership between the Health & Service Equity Transformation (HSET) team in OIS and the REALD & SOGI section in E&I.

Capacity Building

OHA has undertaken several activities to increase internal and external capacity to effectively collect, analyze, and utilize REALD & SOGI data. The value of these capacity building activities has been evident in a change the conversations about REALD & SOGI implementation across OHA and ODHS. Support for REALD & SOGI data collection is building, making it easier to work collaboratively across divisions and programs. This work is a required prerequisite to achieve data equity. See Table eight below for a summary of capacity building (both external and internal) opportunities provided by the OHA REALD & SOGI Section.

Table 9: Capacity Building Activities

Project	Dates	Notes
Data Feminism Book Club	Oct 2022 - Feb 2023	 With HB 3159 staff – weekly sessions on data equity concepts and team building; 18 participants across OHA and ODHS
Innovative Data Practices Learning Collaborative	2022-2023	 Designed to study, learn, and engage with data in equitable and innovative ways. 23 participants Completed 13 sessions; culminated in June 2023
Data Equity	2023- 2024	Designed to study, learn, and engage with data equity principles

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Learning Collaborative		 23 participants; completed 19 sessions; culminated in June 2024 Adopted a 'train the trainer' model to expand training capacity and trained 3 facilitators.
Data Analytic Institute	April 2023 July 2023 October 2023	 1st cohort: 44 (of over 60 applicants) 2nd cohort: 38 3rd cohort with 66 analysts and data leaders from all 16 CCOs
SOGI Community of Practice	August 2022 and May 2023	 Monthly CoP sessions focused on building internal capacity within OHA and ODHS 50 unique attendees and an average of 20 participants per meeting.
SOGI Learning Collaborative	Spring 2023 Cohort November 2023 Cohort	 Spring Cohort consisted of 3 one-to-two-hour sessions to prepare health systems to collect SOGI data in alignment with Oregon's planned SOGI data collection standards; 233 individuals participated in at least one session. The November cohort was a single full-day event with approximately 90 attendees with the goal of providing foundational knowledge of SOGI concepts and reasoning in preparation for the Rulemaking Advisory Committee (RAC) process to establish SOGI data collection standards.

Training and Education

Data Equity & Data Justice

Beginning in October 2022, a book club was convened with 18 participants across OHA & ODHS to discuss research and best practices related to data equity and data justice. The book club participants were assigned to read one chapter each week from the Data Feminism Book. The book club met from October 2022 to February 2023. The book club was planned to run simultaneously with *Data Equity Learning Collaborative (DELC)* to train, build capacity, and network with OHA and ODHS employees who interact with REALD & SOGI data and policy. The DELC provides space for peers to collaboratively study, learn, and engage with data equity principles. The first cohort, with 19 participants, convened in October 2022 and completed 9 sessions in June 2023. In planning for the DELC 2024, the DELC workgroup combined the elements of book club into the learning collaborative. The second cohort completed 13 sessions. The second cohort culminated on June 4th, 2024, with 23 graduates. The DELC has adopted a 'train the trainer' model to expand training capacity. Thus far, 3 facilitators have been trained from Health Policy and Analytics, the Office of Information Systems, and the Health Systems Division.

Data Analytic Institute

Beginning in 2023, the REALD & SOGI team designed a curriculum for the REALD & SOGI Data Analytic Institute (DAI), a 3-day training geared toward analysts and managers using REALD & SOGI data across OHA and ODHS. The goal of the institute was to build capacity for data equity within OHA and ODHS by sharing best practices for processing, analyzing, and reporting REALD & SOGI data.

The first cohort was launched in April 2023 and the second cohort was launched in July 2023. Each cohort had 10 learning modules, totaling over **24** hours of presentation content. In addition, institute participants completed daily

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quizzes and worked in small groups on a final data visualization project. Across the two cohorts, there were 83 analysts and managers representing a variety of divisions and agencies: 38 from Health Policy and Analytics Division, 24 from Public Health Division, 6 from what is formerly known as the Health Systems Division, 12 from ODHS, 1 from the Office of Information Services and 2 external partners from OHSU. Graduates of the institute earned a certificate of completion; ongoing access to materials, additional technical assistance on REALD & SOGI during monthly DAI office hours, and a private Microsoft Teams Community of Practice channel; and a shorter turnaround time on requests for review from the REALD & SOGI team. To support CCOs' understanding and use of the REALD & SOGI data for identifying and addressing health inequities in their member populations, the DAI was adapted for a third cohort comprising 66 analysts and data leaders from all 16 CCOs. As part of graduation, analysts from all CCOs were required to develop proposals on how they would use the REALD & SOGI data for identifying and eliminating inequities. Our team is planning to provide technical assistance to CCOs to implement their proposals, collect and analyze data. Future reports to the legislature will highlight some exciting results from these innovative research engagements with CCOs. The REALD & SOGI team plans to continue offering additional DAI cohorts to both internal OHA/ODHS analysts as well as CCO analysts on a recurring basis.

Sexual Orientation and Gender Identity (SOGI) Learning Opportunities

In preparation for the establishment of SOGI data collection standards, the Section engaged a contractor, Oregon AIDS Education and Training Center (OR AETC), to host a *SOGI Data Collection Community of Practice* and an internal *SOGI Learning Collaborative*. The SOGI Data Collection Community of Practice provided peer-to-peer learning to OHA and ODHS staff and leadership involved in the development and implementation of SOGI data collection. The meetings featured topical presentations from experts as well as check-ins and discussion about participants' experiences, successes, and concerns. This community of practice consisted of 10 meetings between August 2022 and May 2023 with 50 unique attendees and an average of 20 participants per meeting. A second iteration of the Community of Practice will launch in Summer 2024.

The REALD & SOGI Section engaged a contractor, the Oregon Aids Education and Training Center, to lead two externally facing SOGI Learning Collaboratives (see Table Six above). The first SOGI Learning Collaborative consisted of three 1–2-hour sessions in Spring 2023. The goal of these session was to prepare health systems to collect SOGI data in alignment with Oregon's planned SOGI data collection standards. Approximately 233 individuals participated in at least one session of this learning collaborative. The second SOGI Learning Collaborative was conducted as a single full-day event on November 2, 2023, with approximately 90 attendees. This second iteration was conducted with the goal of providing foundational knowledge of SOGI concepts and reasoning in preparation for the Rulemaking Advisory Committee (RAC) process.

Communications, Resources, Tools and Materials

The expansion of staffing in the REALD & SOGI Section in the Spring of 2024 is leading to significant growth in the Section's capacity to effectively communicate with partners, internally and externally which allowed for the following activities to be initiated:

- Updating the <u>REALD & SOGI implementation Guide</u> using a web-based format
- Creating a series of one-pagers to support the collection and use of the data by internal and external partners
- Developing cross-walks to assist analysts in rolling up to meet federal reporting requirements.
- Updating the language lists associated with the data dictionary.
- Updating and maintaining the <u>REALD & SOGI website</u>, including up-to-date and clear communication of reporting requirements and timelines

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- Updating all REALD & SOGI written materials for greater accessibility
- Ensuring the translation and accessibility of all REALD & SOGI data collection instruments

Additionally, the **SOGI Data Collection Toolkit** is in developed in partnership with a contractor and includes materials such as a glossary of SOGI terms, a crosswalk to map responses to Oregon's SOGI questions to the Uniform Data System (UDS), a SOGI Response Matrix, and FAQ videos.

Community Engagement Team

The REALD & SOGI Community Engagement Program was established in Fall 2023 following the approval of four community-facing positions in the REALD & SOGI Section. The intent of the Program is to ensure ongoing and reciprocal engagement with communities in the continuous improvement of REALD & SOGI implementation. This program includes the establishment and maintenance of the REALD & SOGI Community Workgroup as well as direct outreach to communities most impacted by health inequities.

Provider Engagement Team

The REALD & SOGI Section is currently in the process of hiring and onboarding a Provider Engagement Team that will be responsible for assessing the needs of healthcare providers across Oregon regarding full implementation of REALD & SOGI data collection and developing and implementing interventions to address those needs. We anticipate that these interventions will include a combination of training, technical assistance, and materials development. The work of this team will reduce the perceived burden of implementing REALD & SOGI among healthcare providers and greatly increase the capacity of OHA to support REALD & SOGI compliance statewide.

Grant Program

In addition to the development of the Registry and Repository, HB 3159 (2021) requires that OHA "develop and administer a grant program to provide funding for the purpose of supporting safe data collection by community health organizations and community-based groups with demonstrated experience serving tribal communities, communities of color, LGBTQ+ people, people with disabilities, people who speak primary languages other than English and other underserved populations." To fulfill this mandate, the REALD & SOGI Section is currently undergoing a rulemaking process to establish the rules to govern the grant program. The initial round of funding from the grant program is anticipated to be dispersed in Spring 2025. Through the training of trainers, these grants will help to ensure that the implementation of REALD & SOGI data collection by health care providers is culturally responsive and trauma-informed.

Technical Assistance and Support

The REALD & SOGI team collaborated with Divisions across OHA & ODHS to provide technical assistance on projects and reports. Technical assistance consisted of providing Repository data, guidance on best practices on how to analyze REALD & SOGI data, guidance on best practices for data visualization, assistance with providing context for REALD & SOGI data and writing up results. See below for list of reports that the REALD & SOGI team provided support for:

- 2017-2022 1115 Waiver Summative Report submitted to CMS
- CCO Metrics Equity Centered Benchmarking Data Feasibility Report
- Consumer Assessment of Healthcare Providers and Systems (CAHPS)
- Evaluation of the Effectiveness of Health Care Provider Incentive Programs in Oregon

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- Healthcare Workforce Diversity Report
- The Diversity of Oregon's Licensed Health Care Workforce
- The Healthy Oregon People Report

Additionally, the following is a list of all dashboards for which the REALD & SOGI team provided guidance in terms of analytics and visualizations:

- CCO performance metrics dashboard visualizations (2021, 2022, 2023 coming soon)
- Medicaid member dashboard visualizations
- Mpox dashboard
- PHD HIV in Oregon dashboard
- Systems of Care dashboard

While the REALD & SOGI team have been able to fulfill most of the technical assistance needs across OHA, inadequate staffing hinders the ability to meet the continuously growing need for technical assistance as many OHA Divisions work towards full implementation of REALD & SOGI. Future work includes technical assistance with the implementation of REALD & SOGI data collection in the All Payer All Claims data system and other data across divisions in OHA.

Other Projects

As REALD & SOGI implementation deepens within OHA, there is need for additional projects in response to requests and or concerns.

Disaggregated REALD denominators for rate analyses. During the pandemic, OHA contracted with Portland State University to develop county-wide denominators for aggregated race/ethnicity categories for use by analysts. We have expanded this contract to include disaggregation by all REALD domains using Census data. We expect to share the results of this project on our website by late Fall of 2024.

Longitudinal survey. OHA is currently developing a longitudinal survey to test the validity of the REALD & SOGI questions as measures of exposure to systems of oppression resulting in health inequities. This survey will launch in 2024 and is expected to help ascertain the degree to which these questions perform as expected. The longitudinal element is essential to discern the salience of identities over time in response to exposure of discrimination and stigma.

REALD & SOGI Employee Survey. OHA developed a REALD & SOGI Employee Survey designed to compensate for the limitations of demographic data captured in Workday. The survey was launched in October 2023. As of May 2024, 408 unique respondents passed through authentication process. With expanding contact list pool to 6398 employee IDs, the response rate is currently 6.4%. With REALD & SOGI new data collection standards in development, the team is in the process of updating the survey according to the new standards. The team will close the old survey and open the new survey once the standards are finalized.

Workforce Diversity. Important to the agency's goal to eliminate inequities is achieving workforce parity in relation to the Oregon population we serve. The REALD & SOGI team developed metrics for evaluating workforce diversity based on the racial, ethnic, gender and disability composition with respect to overall workforce, retention, separation and in management positions. The team also manages an innovative dashboard visualization of all five

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metrics with division level filters. Data from the workforce diversity performance metrics is also utilized for other state and federal reporting requirements including the Equity Advancement Report, equitable hiring policy and tool kit development, and for the agency's current five-year strategic plan. The plan is to integrate data from the employee intake survey to expand the domains of measurement and comply with REALD & SOGI requirements.

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Appendix

Appendix A. 2020 REALD Template

Oregon Department of Human Services (RFALD) (REALD)



These questions are optional and your answers are confidential. We would like you to tell us your race,

an dial 711. Please contact	Medical r	ages, large print, braille, or a format you at record number (if applicable): nitial: Last name:	prefer. We accept all relay calls or you Date of birth:
	scribes your	ity, tribal affiliation, country of origin, racial or ethnic identity? Please check American Indian and Alaska Native American Indian Alaska Native Canadian Inuit, Metis, or First Nation Indigenous Mexican, Central American, or South American Black and African American African American Ethiopian Somali Other African (Black) Other Black Middle Eastern/North African Middle Eastern	
	or primary rade primary rade primary rade it is pri	ry above, is there <u>one</u> you think of as yo cial or ethnic identity above. N/A sial or ethnic identity. Doi ncial.	A. I only checked one category above. n't know n't want to answer

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					_						$\overline{}$
La	nguaç	ge (Interprete	rs are available								
						ou/the	e person is und	er a	ge 5		
4a. What language or languages do you use at home?											
4b.	4b. In what language do you want us to communicate in person, on the phone, or virtually with you?										
4c.	In wha	at language do <u>y</u>	you want us to w	rite to you?	<u> </u>						
	•		an <mark>interpreter</mark> fo			-	u?				
	☐ Yes ☐ No ☐ Don't know ☐ Don't want to answer										
l	 5b. If you need or want an interpreter, what type of interpreter is preferred? Spoken language interpreter Deaf Interpreter for DeafBlind, additional barriers, or both 								vro or both		
l			n Language inter	nreter			: sign language (15, 01 00111
l		Other (please		protor		Jontaot	oigii idiigaago (OL,	intorpro	toi	
		••	to question 7 if	vou do not	use a land	iuage (other than Engl	ish o	r sian la	anguage	
6.	How w	ell do you spea				,				JJ.	
(1	■ Ve	ry well	■ Well 🗖 I	Not well	■ Not	at all	■ Don't kno	w	■ Do	n't want t	o answer
\succ			find h lul	d oom:!!	Manar		I		_	_	\equiv
			us find health an I without function			Yes	*If yes, at what age did	No	Don't know	Don't want to	Don't know what this
			al. (*Please write				this condition		KIIOW	answer	question is
			cquired this cond		on't want t	0	begin?				asking
7.			ant to answer the ou have serious (oaring?						
8.		wearing glasse	ou have serious s?	aifficulty s	eeing , ever	1					
			Please stop n				der age 5				
9.	Do yo	u have serious	difficulty walki	ng or climb	oing stairs	?					
10.			l, mental or emot			1					
			lty concentratin	g, rememb	ering or						
		ng decisions?									
11.			ty dressing or ba								
12.			difficulty learni	ng how to	do things						
,-		people your a									
13.			stomary) langua Ity communicati								
			ng understood by		mpie						
			Please stop no	•	he person	is un	der age 15				
14.	Becau	ise of a physic	al, mental or em								
	you ha	ave <mark>difficulty d</mark>	oing errands ald								
		r's office or sho									
15.			difficulty with the								
			ngs, controlling ons or hallucina		nor, or						
<u> </u>								20	0 27727	72 MCC 0	074 (02/24)
Prir	nt	Save	Reset					30	0-3/12/	3_IVISU U	074 (02/24)

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Appendix B. 2024 REALD & SOGI Template

Race, Ethnicity, Language, Disability, Sexual Orientation and Gender Identity (REALD and SOGI) for Adults Aged 12 and Up

We need to know some things about you, like your race, gender, and disability. This helps us understand how to give everyone the best care and services, no matter who they are. You don't have to answer these questions if you don't want to. You can select "don't want to answer" or "don't know".

You can get this document in other languages or alternate formats (large print, braille, your
preference) free of charge. To request these or other accommodations, contact [Program
Contact name] at [email] or [phone number]. We accept all relay calls, or you can dial 711.
Today's date: (MM/DD/YYYY) Medical record number (if applicable): Date of birth: (MM/DD/YYYY)
What full name would you like us to use?
First name(s): MI: Last name(s):
Is this your local name? \(\Pi \) Vos \(\Pi \) No. If not list your local name.
Is this your legal name? Yes No If not, list your legal name: First name(s): Last name(s):
Trist name(s).
Who is answering these questions? Select all that apply.
☐ Self ☐ Interpreter or other support person
☐ Parent, guardian, or other family member ☐ Not listed, specify:
Language
1a. Do you only use English at home? Select one.
Yes □ No □ Don't know □ Don't want to answer
1b. Do you need or want any of the following for us to communicate with you?
☐ Yes - Assistive Listening Device such as an FM or ☐ Yes - ☐ Don't know
Loop. Specify: CART/Captioning Don't want to
□ No answer
Skip to question 4 if you only use English at home and do not need interpretation
2a. What language(s) do you use at home?
2b. In what language do you want us to communicate with you?
2c. In what language do you want us to write to you?
2d. Do you need or want an interpreter?
☐ Yes ☐ No ☐ Don't know ☐ Don't want to answer
2e. If yes, select all that apply.
☐ Spoken language interpreter
Sign Language: ☐ Certified Deaf Interpreter for DeafBlind.
☐ American Sign Language additional barriers, or both
☐ Mexican Sign Language ☐ Contact sign language (PSE)
☐ Tactile/Pro-Tactile Sign Language ☐ Another sign language not listed. Specify:
3. How well do you speak English? Select one.
□ Very well □ Well □ Not well □ Not at all □ Don't know □ Don't want to answer

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Functional Difficulties								
4. Are you deaf or do you have serious difficulty hearing	g?							
☐ Yes – This condition began at age: ☐ No	☐ Don't know ☐ Don't want to answer							
5. Are you blind or do you have serious difficulty seeing, even when wearing glasses?								
☐ Yes – This condition began at age: ☐ No	☐ Don't know ☐ Don't want to answer							
6. Do you have serious difficulty walking or climbing sta	airs?							
☐ Yes – This condition began at age: ☐ No	☐ Don't know ☐ Don't want to answer							
7. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating,								
remembering, or making decisions?								
☐ Yes – This condition began at age: ☐ No	☐ Don't know ☐ Don't want to answer							
8. Do you have difficulty dressing or bathing?								
☐ Yes – This condition began at age: ☐ No	☐ Don't know ☐ Don't want to answer							
9. Do you have serious difficulty learning how to do thi	ngs most people your age can learn?							
☐ Yes – This condition began at age: ☐ No	☐ Don't know ☐ Don't want to answer							
10. Using your usual (customary) language, do you have	serious difficulty communicating (for example							
understanding or being understood by others)?								
☐ Yes – This condition began at age: ☐ No	☐ Don't know ☐ Don't want to answer							
☐ Don't know what this question is asking								
Skip to question 13 if you/the person is under age 15								
11. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as								
visiting a doctor's office or shopping?								
☐ Yes – This condition began at age: ☐ No								
12. Do you have serious difficulty with the following: m	ood, intense feelings, controlling your behavior, or							
experiencing delusions or hallucinations?	□ Don't know. □ Don't work to come							
☐ Yes – This condition began at age: ☐ No	☐ Don't know ☐ Don't want to answer							
☐ Don't know what this question is asking 13. If you identify as someone with a disability, or as ha	aving a physical montal amotional cognitive or							
intellectual condition, describe your disability or co								
Skip to question 15 if "Yes" was not selected fo								
13 did not apply to you/the person	The result of the second secon							
14a. If you identify as someone with a disability, or as h	naving a physical, mental, emotional, cognitive, or							
intellectual condition, do you need or want disabil								
14b. If yes, select all that apply and enter additional de								
☐ Alternate formats: ☐ Environmental and sensory: ☐								
☐ Building access: ☐ Equipment access:								
☐ Communication access (in-person, print materials,	☐ Other staff support:							
electronic):	☐ Not listed. Specify:							
☐ Coordinating and scheduling care or services:	☐ Don't know							
	□ Don't want to answer							

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Race and Ethnicity								
15. How do you identify your race, ethnicity, tribal affiliation, country of origin, or ancestry?								
16. Which of the following describes your racial or ethnic identity? Select all that apply and enter additional								
details in the spaces below.								
	American Indian and Alaska Native – Provide details below.							
☐ Alaska Native ☐ Canadian Inuit, Metis, or First Nation								
☐ American Indian ☐ Indigenous Mexican, Central American, or South American								
Enter details, for example, Inuit or Haida, Confederated Tribes of Siletz Indians, Navajo, Aztec, Maya, etc.								
Asian – Provide details below.								
☐ Afghan	☐ Communities of	☐ Indonesian	☐ Pakistani	☐ Vietnamese				
☐ Asian Indian	Myanmar	☐ Japanese	☐ South Asian	LI VICTIONICSC				
☐ Cambodian/Khmer	☐ Filipino/a	☐ Korean	☐ Taiwanese					
☐ Chinese	☐ Hmong	☐ Laotian	☐ Thai					
1	, Mongolian, Malaysian, Uz							
	an – Provide details below.			-				
☐ African American	☐ Ethiopian	☐ Jamaican	☐ Somali					
☐ Afro-Caribbean	□ Haitian	☐ Nigerian						
Enter details, for example	e, Trinidadian, Ghanaian, Co	-						
Hispanic and Latino/a/x/e	– Provide details below.							
☐ <u>Afro-Latino</u> /a/x/e	☐ Cuban	☐ Guatemalan	☐ Puerto Rican	☐ South				
☐ Central American	□ Dominican	☐ Mexican	☐ Salvadoran	American				
Enter details, for example, Colombian, Honduran, Spaniard, etc.								
Jewish – Provide details below.								
☐ Ashkenazi	☐ Sephardi		example, Mizrahi, e	ic				
	ican/SWANA – Provide deta							
☐ Egyptian	☐ Iranian	☐ Lebanese	☐ Syrian					
☐ Iraqi	☐ Israeli	☐ Palestinian	☐ Turkish					
	e, Moroccan, Yemeni, Kurdis fic Islander – Provide details							
			□ Nation	П С				
CHamoru (Chamorro)	☐ Communities of the	☐ Fijian	☐ Native	□ Samoan				
, ,	Micronesian Region	☐ Marshallese	Hawaiian	☐ Tongan				
White – Provide details be	e, Chuukese, Palauan, Tahiti alow	ian, etc.						
	☐ Irish	☐ Polish	Russian	☐ Slavic				
☐ English								
German	☐ Italian	Romanian	☐ Scottish	☐ Ukrainian				
Additional categories	e, French, Swedish, Norwegi	an, etc.						
	istad Spacifu	☐ Don't know	☐ Don't want to ar	SCHOR				
☐ Another category not li	han one category, is there o							
☐ Yes. Circle your	nan one category, is there t ☐ I don't have just one	ne you trillik of as ☐ No. I identify	Not applicable.					
primary racial or ethnic	primary racial or ethnic	as Biracial or	I only checked one					
identity above.	identity.	Multiracial.	category above.	answer.				

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Sexual Orientati	on and Gender Iden	tity	
18. Describe your gen	der in any way you prefer	:	
19. What is your gend	ler? Select all that apply.		
☐ Girl or woman	☐ Demiboy	☐ Not listed, my gender is	: 🗆 Don't know
☐ Boy or <u>man</u>	Demigirl	. , 5	☐ Don't know what this
☐ Nonbinary	☐ Genderfluid	☐ I have a gender identity	question is asking
☐ Agender/No gende		not listed here that is	☐ Don't want to answer
☐ Bigender	☐ Questioning/Explo	ring specific to my ethnicity:	
L bigender	ш фасытыны глуго		
20. Are you transgend	ler?		
☐ Yes	□ Questioning/Explo	ring 🔲 Don't know what this qu	uestion is <u>asking</u>
□ No	☐ Don't know	☐ Don't want to answer	
21. What is your sex?			
☐ Female	☐ Intersex	☐ Don't know	
☐ Male	☐ Not listed, my sex	is: Don't want to answer	
22. Describe your sex	ual orientation or sexual id	lentity in any way you prefer:	
23. What is your sexu	al orientation? Select all th	at apply.	
☐ Same-gender lovin	g 🔲 Straight or heterose	exual Questioning/Exploring	☐ Don't <u>know</u>
☐ Lesbian	☐ Asexual Spectrum	□ Not listed, my sexual	☐ Don't know what this
☐ Gay	☐ Queer	orientation is:	question is asking
☐ Bisexual	□ Pansexual		☐ Don't want to answer
Note. The template for	or children up to age 14	(age 13 and 14 by provider disc	cretion) is the same as the
a simplified set of SC	GI questions:		
Cours Orientation	and Gender Identity		
16. Are you currently: Sele			
□ A boy		□ Don't <u>know</u>	
□ A girl		☐ Don't know what this question is askin	ne l
☐ Both a boy and a girl		☐ Don't want to answer	-
	☐ It changes over time		
17. What is your sex?			
☐ Female		Don't want to answer	
☐ Male	☐ Don't know [Not listed my sex is:	

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Appendix C. REALD & SOGI Inventory of Non-Applicable Data Sources

Name of Data Source	Agency	Agency /	Source Type	Level of
		Division		Control
DAS/HR - Workday	Shared/DAS/Many	DAS/HR	Surveys	High
Integrated Client System (ICS)	ODHS	ODHS	Linked Data Systems	Low
DHS Volunteer Database	ODHS	ODHS	Surveys	High
Health Professional Shortage Areas & Medically Underserved Areas	ОНА	НРА	Providers/Insurers	Medium
Decision Support/Surveillance & Utilization Review System (DSSURS)	ОНА	HSD	Linked Data Systems	Low
Oregon Medicaid Management Information System	ОНА	HSD	Linked Data Systems	Low
ASPEN Minimum Data Set (MDS)	ОНА	HSD	Providers/Insurers	Medium
Birth Anomalies Surveillance System (BASS)	ОНА	PHD	Linked Data Systems	Low
Matched Infant Death	ОНА	PHD	Linked Data Systems	Low
OR Violent Death Reporting System	ОНА	PHD	Linked Data Systems	Low
Oral Health Surveillance System	ОНА	PHD	Linked Data Systems	Low
Healthcare Associated Infections	ОНА	PHD	Providers/Insurers	Medium
Oregon Pandemic Emergency Response Application (OPERA)	ОНА	PHD	Providers/Insurers	Medium
At Risk Identification Alerting System (ARIAS)	ОНА	PHD	Surveys	High
ReproHealth - Program Client Satisfaction Survey	ОНА	PHD	Surveys	High
SMILE Survey	ОНА	PHD	Internal Database	High

Note. n = 16; 18.2% of all monitored data systems (N=88). "Non-applicable" refers to data systems that are applicable to ORS 413.161 but are exempt or inactive or are "linked" or downstream data systems that do not collect REALD & SOGI data directly. "Level of control" refers to the extent OHA/DHS staff can ensure compliance (e.g. have on changes to data elements collected as well as how the data is collected). Medium level of control refers to those systems that ultimately will be in compliance once the HB 3159 Registry/Repository system goes live (expected 2026/27). Level of control is not dependent on resources or funding availability.

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Appendix D. REALD & SOGI Inventory of Applicable Data Sources

Name of Data Source	Agency	Agency /	Source Type	Level of	Status
		Division		Control	
211 Info	Shared/DAS/Many	Shared/Many	Other External	Low	Incompliant
CASPER (Complaints, Actions, Services Programs Evaluations)	Shared/DAS/Many	Shared/Many	Surveys	High	Incompliant
CCLP (Children's Care Licensing Program)	ODHS	ODHS	Surveys	High	Incompliant
CFPRP (Child Fatality Prevention and Reporting Program)	ODHS	ODHS	Surveys	High	Incompliant
Express Payment and Reporting System (eXPRS)	ODHS	ODHS	Surveys	High	Incompliant
ORCAH (Oregon Child Abuse Hotline)	ODHS	ODHS	Surveys	High	Incompliant
RPCP (Resource Parent Certification System)	ODHS	ODHS	Surveys	High	Incompliant
Traditional Health Worker Registry	OHA	E&I	Surveys	High	Incompliant
Hospital Discharge Data (HDD)	OHA	HPA	Providers/Insurers	Medium	Incompliant
PEBB/OEBB Enrollment	OHA	HPA	Surveys	High	Incompliant
Dissolution of Domestic Partnership	OHA	PHD	Other External	Low	Incompliant
Divorce	OHA	PHD	Other External	Low	Incompliant
Marriage	OHA	PHD	Other External	Low	Incompliant
OR Registered Domestic Partnership	OHA	PHD	Other External	Low	Incompliant
ALERT Immunization Information System (IIS)	OHA	PHD	Providers/Insurers	Medium	Incompliant
Death with Dignity	OHA	PHD	Providers/Insurers	Medium	Incompliant
Dental Sealant Program	OHA	PHD	Providers/Insurers	Medium	Incompliant
Early Hearing Detection & Intervention (EHDI)	OHA	PHD	Providers/Insurers	Medium	Incompliant
Electronic Survey System for Early Notification of Community- Based Epidemics	ОНА	PHD	Providers/Insurers	Medium	Incompliant
Environmental Public Health Tracking	OHA	PHD	Providers/Insurers	Medium	Incompliant
Fetal Death	OHA	PHD	Providers/Insurers	Medium	Incompliant
ImageTrend EMS License Management System (LMS)	OHA	PHD	Providers/Insurers	Medium	Incompliant
Induced Termination of Pregnancy	OHA	PHD	Providers/Insurers	Medium	Incompliant
LIMS - Neometrics	OHA	PHD	Providers/Insurers	Medium	Incompliant
LIMS - Orchard	OHA	PHD	Providers/Insurers	Medium	Incompliant
Newborn Screening	OHA	PHD	Providers/Insurers	Medium	Incompliant
OR EMS Information System (OR-EMSIS)	OHA	PHD	Providers/Insurers	Medium	Incompliant
OR State Cancer Registry (OSCAR)	OHA	PHD	Providers/Insurers	Medium	Incompliant
OR Trauma Registry	OHA	PHD	Providers/Insurers	Medium	Incompliant

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OR Workers Compensation Division (OWCD) & Private Insurance	1				1
Carrier	ОНА	PHD	Providers/Insurers	Medium	Incompliant
OVERS - Death Certificate	ОНА	PHD	Providers/Insurers	Medium	Incompliant
Pesticide Exposure Safety & Tracking (PEST)	ОНА	PHD	Providers/Insurers	Medium	Incompliant
Prescription Drug Monitoring Program	ОНА	PHD	Providers/Insurers	Medium	Incompliant
SBHC Encounter Database	ОНА	PHD	Providers/Insurers	Medium	Incompliant
SBHC Patient Satisfaction Survey	ОНА	PHD	Providers/Insurers	Medium	Incompliant
ScreenWise client database (SWAN)	ОНА	PHD	Providers/Insurers	Medium	Incompliant
Electronic License Tracking Environment (eLITE)	ОНА	PHD	Surveys	High	Incompliant
Medical Monitoring Project (MMP)	ОНА	PHD	Internal Database	High	Incompliant
National HIV Behavioral Surveillance (NHBS)	ОНА	PHD	Internal Database	High	Incompliant
OR Medical Marijuana Registry	ОНА	PHD	Surveys	High	Incompliant
OR Psilocybin Services Training Program, Licensing, and					
Compliance	ОНА	PHD	Surveys	High	Incompliant
GetCare	ODHS	ODHS	Surveys	High	Planned/Partial
OR Access (Oregon Automated Computer Capture & Storage					
System)	ODHS	ODHS	Surveys	High	Planned/Partial
ORKIDS (Oregon Automatic Child Welfare Information System)	ODHS	ODHS	Surveys	High	Planned/Partial
Universal Provider Portal	ODHS	ODHS	Surveys	High	Planned/Partial
VRD ORCA (Oregon Rehabilitation Case Automation)	ODHS	ODHS	Surveys	High	Planned/Partial
Health Care Interpreter Registry/Application	ОНА	E&I	Surveys	High	Planned/Partial
All Payer All Claims (APAC)	OHA	HPA	Providers/Insurers	Medium	Planned/Partial
Health Care Workforce Reporting Program Database	OHA	HPA	Internal Database	High	Planned/Partial
Acute Care Reporting (CS-ACR)	OHA	HSD	Providers/Insurers	Medium	Planned/Partial
Resilience Outcomes Analysis & Data Submission System (was					
MOTS)	ОНА	HSD	Providers/Insurers	Medium	Planned/Partial
Pregnancy Risk Assessment Monitoring System (PRAMS)	ОНА	PHD	Providers/Insurers	Medium	Planned/Partial
Behavioral Risk Factor Surveillance System (BRFSS)	ОНА	PHD	Internal Database	High	Planned/Partial
Early Childhood Health in Oregon (ECHO)	ОНА	PHD	Internal Database	High	Planned/Partial
ORCares	ОНА	PHD	Surveys	High	Planned/Partial
OTIS	OHA	PHD	Surveys	High	Planned/Partial
Student Health Survey	ОНА	PHD	Internal Database	High	Planned/Partial
IE/ONE	Shared/DAS/Many	Shared/Many	Surveys	High	Compliant
Centralized Abuse Management (CAM)	ODHS	ODHS	Surveys	High	Compliant

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SACU (Stabilization and Crisis Unit)	ODHS	ODHS	Surveys	High	Compliant
SSP Well-Being Survey	ODHS	ODHS	Internal Database	High	Compliant
DELTA Membership Applications	ОНА	E&I	Internal Database	High	Compliant
Regional Health Equity Coalition (RHEC) Membership Application	ОНА	E&I	Internal Database	High	Compliant
Consumer Assessment of Healthcare Providers & Systems Survey	ОНА	HPA	Internal Database	High	Compliant
Health Evidence Review Committee - Membership Application	ОНА	HPA	Internal Database	High	Compliant
Mental Health Statistics Improvement Program Survey (MHSIP)	ОНА	HPA	Internal Database	High	Compliant
OHPB Committee Applications	ОНА	HPA	Internal Database	High	Compliant
OR Health Insurance Survey (OHIS)	ОНА	HPA	Internal Database	High	Compliant
Avatar	ОНА	OSH	Surveys	High	Compliant
OR Public Health Epidemiologists' User System (Orpheus)	ОНА	PHD	Providers/Insurers	Medium	Compliant
OVERS - Birth Certificate	ОНА	PHD	Providers/Insurers	Medium	Compliant
Reproductive Health Access Fund (RHAF)	ОНА	PHD	Surveys	High	Compliant

Note. n = 72; 81.8% of all monitored data systems (N=88). "Applicable" refers to data systems that are applicable to ORS 413.161 and excludes systems that are exempt, inactive or are "linked" or downstream data systems that do not collect REALD & SOGI data directly (See Appendix D for a summary of these systems). "Level of control" refers to the extent OHA/DHS staff can ensure compliance (e.g. have on changes to data elements collected as well as how the data is collected). Medium level of control refers to those systems that ultimately will be in compliance once the HB 3159 Registry/Repository system goes live (expected 2026/27). Level of control is not dependent on resources or funding availability.

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