
2018 Status Report on the Implementation of the Race, Ethnicity, Language and Disability (REALD) Standards; ORS 413.161 (HB 2134)



Contents

» Executive summary	3
» Status updates and responses to challenges	3
» Ongoing activities and next steps	5
» Background	6
» Purpose of this report.....	7
» The REALD standards and overview of data sets	7
» Progress, challenges and activities	8
» The Oregon Eligibility (ONE) system	8
» The Integrated Eligibility (IE) system	10
» REALD assessments — beyond the ONE/IE system	10
» Data sets within DHS — gap analysis	10
» DHS Vocational Rehabilitation — system changes and implementation pilot	10
» OHP Member Services move to DHS	11
» Data sets within Shared Services	11
» Data sets within OHA — assessments and progress	12
» OHA resources, technical assistance and presentations.....	13
» OHA REALD Implementation Policy.....	14
» OHA research projects	15
» Other OHA implementation activities	16
» Ongoing activities and next steps	17
» REALD Advisory Committee	17
» OEMS proposed actions	17
» OHA work plans, assessments and monitoring	17
» OHA internal messaging, website and tools	17
» OHA training and technical assistance.....	18
» OHA REALD Governance Committee	18
» OHA Sexual Orientation and Gender Identity Ad Hoc Committee.....	18
» OHA research projects	18
» OHA REALD implementation strategies for external data collectors.....	19
» Appendix A. Detailed REALD data collection template for paper-based surveys	20
» Appendix B. List of DHS/OHA and Shared Services data sets: Level of control and how data is collected.....	22
» Appendix C: OHA data sets (excluding ONE/MMIS) making progress to comply with REALD.....	25
» Appendix D: OHA REALD Implementation Policy	26

Executive summary

In 2013, the Oregon Legislature passed HB 2134. The law directed the Oregon Department of Human Services (DHS) and the Oregon Health Authority (OHA) to work together to improve how race, ethnicity, spoken and written language, and disability (REALD) demographics are collected. This effort gives analysts a uniform, effective way to measure and compare service and health disparities to improve service quality.

The OHA Office of Equity and Inclusion (OEI) developed the REALD data collection standards by collaborating with internal and external stakeholders and researchers. OEI finalized REALD standards in the Oregon Administrative Rules (OAR) 943-070-000 through 943-070-007 in early 2014.

This is the third DHS and OHA legislative report, as directed by HB 2134. The 2018 report describes the progress and challenges in implementing the standards across all data systems and a plan for moving forward.

Implementing REALD is affected by several dynamics that include but are not limited to:

- Types of complexity and diversity of data systems subject to the law's requirements
- Who collects the data (e.g., directly by OHA/DHS/Shared Services staff, or indirectly via external partners (e.g., hospitals))

Status updates and responses to challenges

The Oregon ONE Eligibility (ONE) system

In the last two years, OHA and DHS focused on ensuring Oregon's new online eligibility system became fully compliant with REALD standards. A work group began updating the ONE system in 2016. The group designed, revised, tested and (in May 2017) launched several new questions on the eligibility screens.

Once the paper application has been updated, three other OHA data sets from the Oregon Medicaid Management Information System (OR-MMIS) will also comply with REALD demographic questions.

The Integrated Eligibility (IE) system

DHS is now integrating eligibility determination functionality into ONE for the Non-Modified Adjusted Gross Income (MAGI), Supplemental Nutrition Assistance Program (SNAP), Employment-Related Day Care (ERDC) and Temporary Assistance for Needy Families (TANF) programs. Because of this effort, labeled “Integrated Eligibility,” the method for collecting REALD variables from program applicants will be uniform and consistent.

Analysis of DHS data sets

Due to the extended Integrated Eligibility schedule combining select DHS programs into ONE, the Office of Equity and Multicultural Services (OEMS) asked the Office of Information Services (OIS) to analyze which systems were not affected by IE and would need to become REALD compliant apart from IE. The review noted six DHS systems beyond those integrated into ONE that are currently moving toward compliance. Five systems either do not collect client data or import existing REALD data from other systems. Four will be retired after integration with ONE.

DHS Vocational Rehabilitation is piloting system changes in how VR collects and stores REALD data.

Oregon Health Plan Member Services move to DHS

Because OHP Member Services has transitioned to DHS and OEI originally trained OHA staff members in REALD, the DHS REALD Team and the training group are working to ensure training of DHS staff with the same data maintenance standards and practices. Agency-wide training will follow this effort.

Analysis of OHA data sets

Three HB 2134 assessments identified 117 distinct data sets within OHA. The assessments identified more than 80 data sets not affected by the ONE system or the eventual IE system. Twenty data sets have not yet been assessed. Approximately six stand-alone data sets or surveys beyond the ONE system have increased compliance with the REALD standards.

OHA resources, technical assistance and presentation

Training needs vary in context, format and intended audience(s) depending on the type of data set and whether data collection is internal or external. This diversity in training needs makes creating a one-size-fits-all training difficult. Thus, REALD trainings and presentations are largely done on request.

OHA REALD Implementation Policy

These challenges point to a clear need for a REALD Implementation Policy establishing a REALD compliance accountability process. Leadership approved this policy in June 2018. It created a systemic monitoring and assessment process with accountability for all data systems with REALD application.

Ongoing activities and next steps

REALD Advisory Committee — The REALD Advisory Committee convened to receive updates on REALD progress and provide guidance.

OEMS proposed actions — OEMS will continue to help VR and other DHS data systems become REALD-compliant. OEMS will also continue working with Integrated Client Services to review data quality from REALD collection methods in ONE, VR and other systems as they move toward compliance.

OHA work plans, assessments and monitoring — OHA data owners need to meet the timelines for submitting a work plan to OEI regarding REALD Implementation Policy.

Background

In 2013, the Oregon Legislature passed [HB 2134](#). The law directed the Oregon Health Authority (OHA) and the Department of Human Services (DHS) 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 DHS and OHA programs and activities. Collecting these variables gives analysts a uniform, effective way to measure and compare disparities in services and health. This will improve service delivery quality.

OEI developed the REALD data collection standards through an interactive and thorough process involving committees of internal and external stakeholders and researchers. Standards were based on best equity and inclusion practices. The REALD HB 2134 Subcommittee — consisting of research analysts, program staff and other OHA and DHS staff — met regularly in 2013 to develop the standards. They compared questions from other large surveys, such as from the Council on Quality of Care and Outcomes Research (Q Corp) and the American Community Survey from the US Census Bureau, to find commonalities among the surveys. The Rules Advisory Committee, consisting of external stakeholders, met regularly during this same time and reviewed drafts of questions. The REALD standards were finalized in the Oregon Administrative Rules [OAR 943-070-000 through 943-070-007](#) in early 2014, after a series of public hearings and opportunities for public comment.

In early 2016, POP 201 funded five new positions, filled by April 18, 2016. The Office of Equity and Multicultural Services (OEMS) in DHS and the Office of Equity and Inclusion (OEI) in OHA each received an operations and policy analyst 4 (OPA4) to lead implementation of REALD in their respective agencies as well as community engagement, policy reconciliation and training of program staff on REALD standards and technical systems. The Office of Forecasting, Research and Analysis (OFRA) received an operations and policy analyst 4 (OPA4) and a research analyst 4 (RA4) dedicated to integrating, maintaining and reporting standardized REALD data across programs (including Medicaid) feeding into the Integrated Client Services data system. Shared Services IT received an information systems specialist 8 (ISS8) to assist OFRA staff with their work.

Purpose of this report

DHS and OHA have made two previous reports to legislators, as directed by HB 2134 and the OARs. The [first report](#) to the legislators in 2014 provided a baseline assessment of DHS and OHA data sets and data systems with respect to the REALD standards. In June 2016, DHS and OHA submitted a status report that described progress made and future efforts. As specified in [HB 2134](#) and the [OARs](#), this report provides a description of the standards, progress and challenges in implementing the standards across all data systems as well as a plan for addressing identified challenges.

The REALD standards and overview of data sets

See Appendix A for a snapshot of the required REALD data elements in the paper-based survey. There are three racial ethnic identity questions, seven disability questions and six language questions.

Implementing REALD is complicated by the diversity of:

- Types of data systems (e.g., client-based data systems, survey data, administrative data systems),
- Who collects the data (e.g., directly by OHA/DHS/Shared Services staff, or indirectly via external partners (e.g., hospitals), and
- The degree to which OHA, DHS and Shared Services can directly influence the implementation process. See Appendix B for a list of data sets applicable to the REALD standards by agency and by type of data set (e.g., data collected for administrative purposes, online surveys, client-based data sets), and how data is collected (e.g., directly from individuals or indirectly through external partners). For example, many of the “client/clinical” data sets housed in OHA are derived from electronic medical records collected and stored by external providers. This means that, to comply with the REALD standards, OHA contractors and subcontractors would also need to change their internal data collection systems. The number and diversity of data sets make it hard to apply a one-size-fits-all approach to implementing the REALD standards uniformly and effectively across all data systems with demographic data. These complexities require us to work more strategically in achieving REALD compliance, starting with the data sets in our direct control that will provide long-term value. This report will now discuss the progress made over the past two years, as well as the challenges, starting with one of the largest data sets used by both OHA and DHS.

Progress, challenges and activities

The Oregon Eligibility (ONE) system

More than 80 percent of clients served by DHS/OHA programs receive Medicaid services. As a result, OHA and DHS have focused their efforts in the last two years on ensuring Oregon's new online eligibility system, which is used for Medicaid eligibility determination, became fully compliant with the REALD standards. The Oregon Eligibility (ONE) system went live Dec. 15, 2015.

A work group within OHA Health Systems was convened in 2016 to begin the collaborative and involved process of updating the ONE system. The process included extensive ONE design sessions from January through April 2017. As REALD subject matter experts, OEI and OEMS were both involved in almost daily one-hour ONE design sessions. Most of the work group's recommendations were considered in the redesign of the ONE system. This work included reviewing and finding resolutions and compromises to problems relating to multiple programs with conflicting federal and state requirements being collected using the same eligibility determination system. Following the design sessions, the work group revised, tested and implemented several new questions on the eligibility screens. The change was completed and launched in May 2017.

In August 2017, OEI identified a defect in ONE where REALD demographics were being collected from non-applicants; OEI fixed this defect in November 2017. Furthermore, a request was submitted in 2017 to add a Language Access statement in ONE and was addressed through a business process that did not require a system update. Some of the concerns and conflicting requirements identified in early 2017 during the design sessions were not resolved until after the new ONE was launched in June 2017. For example, some in DHS and OHA were concerned that collecting the REALD questions conflicted with Oregon Governor's Executive Order 17-04, Renewing Oregon's Commitment to Protecting Its Immigrant, Refugee, and Religious-Minority Residents. Consultation with the Department of Justice resolved this concern.

Another concern related to the REALD questions being skippable, even though there was an asterisk denoting required response (including the option to "decline"). This came about because of a concern that requiring applicants to answer the questions could conflict with CMS regulations. This may account for the current large number of nonresponses to REALD questions. However, by early spring 2018, feedback from the Department of Justice cleared this concern. The next generation of the ONE system will require the REALD questions. The Integrated Eligibility system is due to go live Sept. 1, 2019, and then roll out incrementally between Jan. 30, 2020, and Aug. 1, 2020.

The ONE system has two portals for applicants: the ONE Applicant Portal and the Worker Portal. The ONE Applicant Portal is the best and most convenient place for Oregonians to apply for Medicaid, find out if they qualify, and report changes to their household. It is available in English and Spanish. Applicants use the Worker Portal if they do not have access to the internet, read a language other than English or Spanish or prefer another method use the Worker Portal. These individuals can apply with the help of a community partner, fill out a paper application or call OHP Customer Service.

While both portals are fully compliant with REALD, the Oregon Health Plan (OHP) paper application for Medicaid services is not yet compliant. To add REALD questions to the paper application, the ONE system had to first be updated to capture and process the information being collected. Over the past few years, the Oregon Health Authority has experienced several challenges to implementing the revised paper application for Medicaid services, including the following:

- Executive leadership in the OHA Director's Office changed, which put a hold on finalizing the application.
- Health Systems Division executive leadership changed twice, which delayed leadership review and approval and
- Oregon Health Plan eligibility services moved to the Department of Human Services (DHS), which added channels of approval. OHA and DHS leadership have agreed on a path to final approval for the paper application for Medicaid services.

After one year of collecting data from OHP applicants in the ONE system, OEI conducted a detailed nuanced data quality analysis that built upon analyses conducted by Office of Forecasting, Research and Analysis (OFRA) researchers. The OFRA analyses suggested a tremendous number of non-responses. Therefore, this assessment sought to learn why the data was missing and research other data quality issues that could inform the Integrated Eligibility system's development and other related data processes. This work will be completed by the end of 2018 and shared with the REALD Advisory Committee in 2019. This will enable everyone involved with REALD to learn more about which standards are up to date, efficient, uniform and consistent with best, promising and emerging practices.

The ripple effects from these efforts are important. Once the paper application has been updated, three other OHA data sets using data from MMIS will also be compliant with REALD demographic questions (see Appendix A) as follows:

- Decision Support Surveillance & Utilization Review System
- Mental Health Statistics Improvement Program Survey, and
- Youth Services Survey, which surveys youth receiving Medicaid.

The Integrated Eligibility (IE) system

DHS is currently in the process of integrating eligibility determination functionality into ONE for the Non-MAGI Medicaid, SNAP, ERDC and TANF programs. This effort has been labeled as Integrated Eligibility (IE). With these DHS program additions to ONE, applicants to each of these programs will encounter the same applicant screens collecting these REALD variables; i.e., the method for collecting REALD variables from applicants to each of these programs will be uniform and consistent.

REALD assessments — beyond the ONE/IE system

Data sets within DHS — gap analysis

Due to the extended Integrated Eligibility schedule combining select DHS programs into ONE, the Office of Information Services requested an analysis to identify systems not affected by IE, and therefore needing to be evaluated for REALD compliance. In 2017, DHS's Office of Equity and Multicultural Services (OEMS) commissioned a review of current DHS systems by the Office of Information Services (OIS). This review focused on systems determined to be out of compliance in their methods for collecting REALD demographics. The review revealed that, beyond the DHS programs integrating with ONE, six DHS systems are in the process of becoming compliant, five either do not collect client information or import existing REALD data from other systems, and four will be retired after their systems are integrated with ONE. See Appendix B for a list of all data sets applicable to REALD.

DHS Vocational Rehabilitation — system changes and implementation pilot

OEMS has put agreements in place for piloting system changes in how the Office of Vocational Rehabilitation (VR) collects and stores REALD data. Specifically, work is in progress to update VR's data system, known as Oregon Rehabilitation Case Automation (ORCA), to receive REALD data. The benefits of piloting REALD collection methods with VR are:

- VR is a small program with offices in all areas of the state.
- The ORCA system is easier for VR and OIS staff to customize. The resulting flexibility has allowed the ORCA system to be the most closely aligned to receive REALD variables.

Implementation of REALD methods in VR will also include a curriculum for staff training. The training will include educating staff on system changes, as well as interview techniques to ensure staff respectfully collect REALD demographics and address client questions. A full communication plan is being developed that will include public service announcements and community partner participation.

By piloting REALD in VR, the project will refine the developing curriculum and training to meet the needs of programs as well as staff. In this effort, the curriculum will be used to train all DHS staff as systems become compliant and REALD data are entered into the system. In the future, as new systems come online for DHS, this curriculum will be embedded into all new system training. One of the important outcomes for this pilot and the training is that staff will see that REALD data allow DHS to understand who our clients are as individuals and to identify underserved populations. By developing strong skills in gathering this data, our staff will know how to respond to questions or concerns by the public around demographic data collection. In addition, they will have the depth of knowledge to articulate the value of this demographic data and application.

OHP Member Services move to DHS

As OHP member services has transitioned to DHS, the DHS REALD team is working with its training group to look ahead and train community partners during the recertification process to ensure that staff are trained with the same standards and practices as the rest of DHS staff, to maintain data standards. OEMS will take this time to get feedback and use the information to enhance the curriculum for the REALD VR pilot and agency-wide training.

Data sets within Shared Services

In addition to the ONE system and MMIS/DSSURS, approximately seven data sets are either shared across OHA and DHS and/or are managed by Shared Services (e.g., OIS, Human Resources) (see Appendix B). These include data sets for PEBB/OEBB (enrollment and claims, DHS volunteer database that includes OHA volunteers as well), the Oregon ACCESS Case Management System, and Workday, planned to launch by the end of 2018.

Technical assistance has been provided to staff in PEBB/OEBB about REALD, and the Oregon ACCESS Case Management System will likely be incorporated into the Integrated Eligibility System. OEI will follow up with the DHR volunteer database data owner later this year. With respect to Workday, DAS has not included the REALD standards and does not plan to do so in the future. As Workday is a DAS statewide data system, OEI is limited in its authority to implement the REALD standards.

Data sets within OHA — assessments and progress

The HB 2134 assessments in 2014, 2016 and 2017 identified 117 distinct OHA data sets through existing documentation of agency data systems, as well as documentation resulting from the 2016 Gap Analysis, which was used to assist the Oregon Health Policy Board to develop a statewide strategic plan for the collection and use of health care data.* After excluding those data sets without demographics, OEI identified more than 80 data sets not affected by the ONE system nor the eventual IE system (see Appendix B for a list of these data sets). More than half of these data sets were assessed in 2014 and again in 2016/17. There are still 20 data sets not yet assessed.

In addition to the ONE system, approximately six other stand-alone data sets or surveys have made progress to increase compliance with the REALD standards. In most cases, these data sets or surveys represent cases in which OHA staff highly control implementation of the REALD standards. See Appendix C for a list of 10 data sets demonstrating improved compliance with REALD standards. Three data sets had seven disability-related questions but did not include the age follow-up question for those who answered affirmatively to any of the disability questions. This may be, in part, because collecting disability as a demographic requires a paradigm shift in thinking about people with disabilities as a health disparity population. However, 90% of OHA data sets do not have all 34 racial and ethnic identity categories (including the “Other Race” option) and/or the six language questions. The low rate of compliance with the language questions may be because some of them do not seem to apply to data sets that are not client-based (e.g., to ensure language access to clients/members in the ONE system).

Q Corp assessment. As mentioned above, implementing REALD is complicated by the data systems’ diversity, how data are collected, and the degree to which OHA/DHS or Shared Services can require external data collectors to use the REALD standards. OEI sought to better understand the gaps in the Race, Ethnicity, Language and Disability (REALD) data collected by health systems and reported to the OHA. OEI contracted with the Oregon Health Care Quality Corporation (Q Corp) to review existing information and interview key stakeholders to better understand the barriers and learn what it would take for those collecting data and submitting the data to OHA to be compliant with REALD data standards. The Q Corp report details the findings of the review and interviews, which were completed between May 17, 2017, and June 28, 2017.

* Detailed information about the Gap Analysis conducted by Q Corp can be found [here](http://www.oregon.gov/oha/HPA/ANALYTICS/Quality%20Metrics%20Committee%20Docs/440-Report-Full_Sept-2016.pdf) or at http://www.oregon.gov/oha/HPA/ANALYTICS/Quality%20Metrics%20Committee%20Docs/440-Report-Full_Sept-2016.pdf.

Multnomah County Health Department REALD needs assessment

Multnomah County Health Department was funded to assess MCHD data systems needs including that of FQHC, EPIC and other data systems feeding data to OHA and/or DHS. This work is ongoing and will help to inform additional systems-level resources needed to implement REALD.

OHA resources, technical assistance and presentations

Training needs vary in context, format and intended audience(s), depending on the type of data set, whether data collection is done internally or externally. The diversity in training needs makes it difficult to create a one-size-fits-all training. For these reasons, REALD trainings and presentations are largely done upon request. OEI also makes available training materials for other programs that want to develop their own trainings. Examples of tailored trainings include a collaboration with OHP Member Services on the curricula for community assistors piloted in June 2017, and again in September 2017. Other examples of tailored presentations provided in the last two years include presentations to OHA's Public Health Scientific Community of Practice (SCoPe), 2018 DELTA leadership cohort, and the Data Quality Assurance Collaborative members (CCOs).

Technical assistance is usually provided to specific staff regarding specific data sets such as the ONE system, TWIST (WIC), Maternal and Child Health survey, licensing boards and database directories of OHP providers. Some of these efforts are time-intensive such as the almost daily design sessions on the ONE system for nearly two months.

Further, to make it easier for OHA staff in implementing REALD, in addition to tailored trainings and technical assistance, OEI has developed the following resources since early 2016:

- **A detailed data collection template**, available in 21 languages that includes all questions needed for full compliance with REALD standards. The template is for OHA programs to use as an optional standalone paper-based survey. The template may also be tailored to meet the needs of specific programs.
- The comprehensive **REALD Implementation Guide**, intended to address the many questions research analysts and data owners have about implementing REALD. In addition to an introduction to REALD and a detailed review of the REALD questions and categories with a series of FAQs, the guide provides specific guidance on work plan development, data collection processes, and analyses and reporting using the REALD categories and questions.
- **Cross-maps** of the REALD questions and categories to the Medicaid Management Information System, which are the federal Office of Management standards.

- A **data brief on the validity** of the American Community Survey disability questions for OHA analysts.
- Additional resource materials such as a one-page “Fast Facts” about REALD and a short informational document about the “White” subcategories.

OHA REALD Implementation Policy

The challenges described above pointed to a clear need for a REALD Implementation Policy that would establish an accountability process for REALD compliance. Therefore, in fall 2016, OEI convened a REALD Implementation Policy Committee with representation from:

- Most OHA divisions
- External stakeholders such as
 - The Coalition of Communities of Color and
 - Multnomah County employees with subject matter expertise in collecting and analyzing disparity data from communities of color and other non-dominant groups.

The committee also decided that there was a need to prioritize data sets because there are many applicable OHA data systems. To do this, OEI and members of the Policy Committee convened **five community meetings** to learn what types of data people were using or wanted to use to address their own health issues. This process resulted in prioritized data sets listed in the policy (Appendix D).

The finalized OHA REALD Implementation Policy includes **timelines** for both work plan completion and REALD compliance. The timelines established considered the prioritization of data sets, as well as the level of control OHA staff have on revisions to data collection tools, and how the data are collected from individuals (directly by OHA or indirectly from external partners) (Appendix D).

This policy:

- Clarified the meaning of the word “practicable”
- Explicated the requirement for analyses and reporting using the granularity captured by the REALD questions or categories
- Established a requirement for a work plan for each data system that is not fully compliant. The work plan serves also as a means for the OEI staff to monitor efforts in REALD implementation, and offer technical assistance as needed.
- Provided an alternate set of language questions to use as a demographic for data systems that do not involve people receiving direct services of some sort.

The policy includes timelines for both work plan completion and REALD compliance (Table 1). The timelines established considered:

- The prioritization of data sets
- The level of control OHA staff have on revisions to data collection tools, and
- How the data are collected from individuals (directly by OHA or indirectly from external partners).

OHA leadership approved the REALD Implementation Policy in June 2018. This created a process for systemic monitoring and assessment with accountability for all data systems applicable to REALD.

Before the end of 2018, OEI plans to disseminate information about the REALD Implementation Policy. This will include the REALD Implementation Guide (and links to REALD webpages).

Table 1. Work plan and compliance timelines from date of passage of implementation policy

	Prioritized data set/data system?	
	Yes	No
Medium to high control & data are collected directly by OHA or OHA data vendor	Work plans: 3 months Compliance: 18 months	Work plans: 6 months Compliance: 36 months
Low control & data are collected directly by external partners	Work plans: 12 months Compliance: 36 months	Work plans: 24 months Compliance: 48 months
Medium to high control & data are collected indirectly by external partners		
Low control & data are collected indirectly by external partners	Work plans: 12 months	Work plans: 24 months
	Compliance: To be determined from the work plan assessment process.	

OHA research projects

Data quality assessment of REALD in the ONE system. After one year of data collection of OHP applicants in the ONE system, OEI conducted a detailed data quality analysis that built on the analyses conducted by researchers in OFRA. The OFRA analyses suggested a tremendous amount of non-responses. Therefore, this assessment sought to learn more about the nature of the non-responses and other data quality issues to inform the Integrated Eligibility system’s development and other related data processes. This work is still in progress but will be completed and shared with the REALD Advisory Committee by the end of 2019. Together with the REALD Advisory Committee, OEI will learn more about how up to date, efficient and uniform the standards are, and how consistent they are with best, promising and emerging practices.

Validity research project. Many discussions held during the design sessions for the ONE system in early 2017 and research analysts asked about the REALD data standards' validity. As a result, OEI decided to design a cross-sectional study to assess the reliability and validity of the REALD data collection standards measurement tool with diverse populations (adolescents and adults) in Oregon. OEI worked in collaboration with partners from the Multnomah County Health Department and the Portland State University Survey Research Lab to develop the research design. OEI is currently in the process of finalizing four versions of an online survey for this project.

Syntax development and data briefs with REALD data. In developing the comprehensive REALD Implementation Guide, OEI realized it would be helpful to give examples of how to analyze and present data based on the REALD standards. The U.S. Census's American Community Survey (ACS) already has six of the REALD disability questions and captures most of the language questions. As a result, OEI developed coding for a statistical software program (Stata) to be able to impute 33 REALD race and ethnicity categories, one language question and six disability questions. This syntax has helped create Oregon-specific demographic profiles based on the REALD standards and the denominators for other types of analyses, such as workforce parity within OHA. Further, this work provided the groundwork for what will be a series of stand-alone data briefs on health and social disparities.

Other OHA implementation activities

In addition to the **five community meetings** convened in Portland, Salem and Eugene to learn what types of data people were using or wanted to use to address their own health issues, OEI staff also conducted several informal focus group meetings with OHA program staff and research analysts. The meetings' goal is to further understand REALD's implementation needs and challenges. OEI also convened several informal focus groups with people with disabilities to learn of their reactions to the disability questions, and the type of messaging or formatting required to make it easier to answer the questions.

Other implementation activities, often done in response to specific questions and concerns, included:

- Research and response to the issue of whether CMS allows the disability questions on the OHP application
- A brief on the validity of six disability questions (used by the Census), and
- A policy analysis of the scope of REALD.

Ongoing activities and next steps

REALD Advisory Committee

The REALD Advisory Committee convened to receive updates on REALD progress and provide guidance. Some of the challenges in convening the committee were due to focusing DHS and OHA staffing resources on the heavy lift in getting the ONE system launched and responding to training and technical assistance needs. While the workload is still intense, OEI and OEMS will develop a regular meeting schedule.

OEMS proposed actions

OEMS will continue to work with VR and other DHS data systems to help them become compliant. OEMS will also continue working with Integrated Client Services in the Office of Forecasting, Research and Analysis to review data quality from methods used to collect REALD demographics in ONE, VR and other systems as they move toward compliance with HB 2134. In cases where data quality is low, OEMS will improve the data collection methods used to collect REALD variables or through continual training.

OHA work plans, assessments and monitoring

OHA data owners are expected to meet the timelines for submitting a work plan to OEI as specified in the REALD Implementation Policy. The first round of work plans were due in December 2018 for data sets with medium to high control, collected directly and prioritized per community meetings done in 2017 (Appendix D, Table 1).

OEI will initiate a third biennial assessment of OHA data systems applicable to REALD in 2020. OEI is designing this assessment to not only capture progress and gaps in meeting the REALD standards, but to learn more about these systems. The more we understand about each system, the more effectively we can provide technical assistance.

OHA internal messaging, website and tools

Now that the OHA Director and the OHA Leadership Team have approved the REALD Implementation Policy, OEI plans to coordinate internal messaging about the REALD Implementation Policy and work plan timelines, along with tools and resources, to the OHA staff responsible for data sets applicable to the REALD standards. OEI will revise an internal video for staff to reflect the current OHA leadership; this video will be disseminated in the coordinated messaging campaign. OEI has also developed templates for brochures and posters about REALD that OHA programs can use.

OHA training and technical assistance

While providing training and technical assistance to staff within OHA over the last two years, OEI laid the groundwork for future partnerships on a larger scale. For example, the Public Health Division is the owner of most OHA data sets applicable to REALD; OEI is helping PHD message about REALD to its employees and tailoring trainings on the policy and work plans. In another example, OEI is providing technical assistance on training and a REALD toolkit for infectious disease case investigators. This toolkit will include many of the resources already developed such as the implementation guide, crosswalk document, scripts, CLAS standards, language access resources, and a list of iLearn trainings related to health equity and cultural responsiveness. OEI also plans to develop several stand-alone interactive trainings for iLearn about REALD, as well as a general video about REALD for the public.

OHA REALD Governance Committee

The OHA REALD Implementation Policy (Appendix D) directed OEI to convene a REALD Governance Committee made up of a representative from each OHA division, a representative from the Health Equity Committee, and three external stakeholders with general knowledge of using data to advance health equity. This committee will advise on:

- Exemptions to the REALD policy
- Modifications to REALD data categories, and
- Questions, implementation progress and other issues that come up requiring decisions by the OHA director or the OEI director. This committee will meet at least three times a year.

OHA Sexual Orientation and Gender Identity Ad Hoc Committee

The OHA REALD Implementation Policy (Appendix D) also directed OEI to begin developing recommendations for data collection standards through a community engagement process. This process includes internal and external stakeholders. It centers on those reflected in and most affected by the gender identity and sexual orientation data collection standards. This is timely due to ACA Section 1557 and recent changes in how gender identity is recorded on drivers' licenses and birth certificates in Oregon.

OHA research projects

Data quality assessment of REALD in the ONE system. As discussed above, this work will be completed by the end of 2018. OEI will share the assessment with the REALD Advisory Committee; together with the REALD

Advisory Committee, OEI will be able to learn more about the extent to which standards are up to date, efficient, uniform and consistent with best, promising and emerging practices.

Validity research project. As discussed above, OEI is currently finalizing four versions of an online survey for this project. We expect to submit an Institutional Review Board application for this study by March 2019. The survey will be “live” for three to six months until enough data have been received from around the state with representation from diverse populations.

Data briefs with REALD data. OEI’s first series of briefs using the American Community Survey data focuses on the social determinants of health for people with disabilities. OEI has developed a draft of the first data brief on the employment of people with disabilities in Oregon; this brief also took an intersectional approach to include race, ethnicity and sex/gender. These data briefs will be published on the OEI website.

OHA REALD implementation strategies for external data collectors

The Q Corp report mentioned above will help OEI take a measured approach to the implementation of the REALD standards. For example, in the REALD Implementation Policy, OEI directed OHA staff with data sets **that rely on data collected indirectly by external partners** to submit a work plan that includes an assessment containing the following elements:

- Required system level changes
- Resources needed to bring the data system into compliance
- The need for data agreements or contracts with subcontractors and external partners, and
- Estimated timelines for full compliance with the REALD standards.

Meanwhile, in 2019, a REALD assessment of the Multnomah County Health Department data systems linked to OHA and DHS data systems, (e.g., WIC and FQHC).

OEI will monitor and find ways to use the information from the Q Corp report, the MCHD Needs Assessment, and the OHA REALD work plans to strategize how to begin implementing REALD with external partners, particularly those who use electronic medical records and already have many of the standards available to them.*

* Specific vocabulary standards for electronic health information are outlined in [45 CFR 170.207](#). These standards include preferred language, sexual orientation, and gender identity.

Appendix A. Detailed REALD data collection template for paper-based surveys

Race, Ethnicity, Language, and Disability (REALD)



These questions are optional and your answers are confidential. We would like you to tell us your race, ethnicity, language and disability background so that we can find and address health and service differences.

1. Do you need written materials in an alternate format (Braille, large print, audio recordings, etc.)?
 Yes No Don't know/Unknown Don't want to answer/Decline
 If yes, which format? _____

Race and Ethnicity

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

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

<p>American Indian or Alaska Native</p> <input type="checkbox"/> American Indian <input type="checkbox"/> Alaska Native <input type="checkbox"/> Canadian Inuit, Metis, or First Nation <input type="checkbox"/> Indigenous Mexican, Central American, or South American	<p>Asian</p> <input type="checkbox"/> Asian Indian <input type="checkbox"/> Chinese <input type="checkbox"/> Filipino/a <input type="checkbox"/> Hmong <input type="checkbox"/> Japanese <input type="checkbox"/> Korean <input type="checkbox"/> Laotian <input type="checkbox"/> South Asian <input type="checkbox"/> Vietnamese <input type="checkbox"/> Other Asian	<p>Black or African American</p> <input type="checkbox"/> African American <input type="checkbox"/> African (Black) <input type="checkbox"/> Caribbean (Black) <input type="checkbox"/> Other Black
<p>Hispanic or Latino/a</p> <input type="checkbox"/> Hispanic or Latino/a Central American <input type="checkbox"/> Hispanic or Latino/a Mexican <input type="checkbox"/> Hispanic or Latino/a South American <input type="checkbox"/> Other Hispanic or Latino/a	<p>Native Hawaiian or Pacific Islander</p> <input type="checkbox"/> Guamanian or Chamorro <input type="checkbox"/> Micronesian* <input type="checkbox"/> Native Hawaiian <input type="checkbox"/> Samoan <input type="checkbox"/> Tongan* <input type="checkbox"/> Other Pacific Islander	<p>Middle Eastern/Northern African</p> <input type="checkbox"/> Northern African <input type="checkbox"/> Middle Eastern
		<p>White</p> <input type="checkbox"/> Eastern European <input type="checkbox"/> Slavic <input type="checkbox"/> Western European <input type="checkbox"/> Other White
		<p>Other Categories</p> <input type="checkbox"/> Other (please list) _____ <input type="checkbox"/> Don't know/Unknown <input type="checkbox"/> Don't want to answer/Decline

4. If you selected more than one racial or ethnic identity above, please **CIRCLE the ONE that best represents your racial or ethnic identity.**

You can get this document in other languages, large print, braille, or a format you prefer. We accept all relay calls or you can dial 711. Contact:

Program:
 Phone:
 Email:

Continued on next page

OHA 0074 (1/18)

Language

5. In what **language** do you want us to:

Speak with you _____

Write to you _____

6. Do you need a **sign language** interpreter for us to communicate with you?

- Yes Don't know/Unknown
 No Don't want to answer/Decline

If yes, which type do you need us to communicate with you?

(ASL, PSE, tactile interpreting, etc.)

7. Do you need an **interpreter** for us to communicate with you?

- Yes Don't know/Unknown
 No Don't want to answer/Decline

8. How well do you speak English?

- Very Well Not at all
 Well Don't know/Unknown
 Not Well Don't want to answer/Decline

Disability Your answers to the questions below help us find health and service differences among people with disabilities or limitations. Your answers are confidential.

9. Are you **deaf** or do you have **serious difficulty hearing**?

- Yes Don't know/Unknown
 No Don't want to answer/Decline

If yes, at what age did this condition begin? _____

10. Are you **blind** or do you have **serious difficulty seeing**, even when wearing glasses?

- Yes Don't know/Unknown
 No Don't want to answer/Decline

If yes, at what age did this condition begin? _____

11. Does a **physical, mental, or emotional condition limit your activities** in any way?

- Yes Don't know/Unknown
 No Don't want to answer/Decline

If yes, at what age did this condition begin? _____

12. What is your age today? _____

Please stop now if the person is under age 5

13. Do you have serious difficulty **walking or climbing stairs**?

- Yes Don't know/Unknown
 No Don't want to answer/Decline

If yes, at what age did this condition begin? _____

14. Do you have **difficulty dressing or bathing**?

- Yes Don't know/Unknown
 No Don't want to answer/Decline

If yes, at what age did this condition begin? _____

15. Because of a **physical, mental, or emotional condition**, do you have serious difficulty:

a. **Concentrating, remembering or making decisions?**

- Yes Don't know/Unknown
 No Don't want to answer/Decline

If yes, at what age did this condition begin? _____

Please stop now if you/the person is under age 15

b. **Doing errands alone** such as visiting a doctor's office or shopping?

- Yes Don't know/Unknown
 No Don't want to answer/Decline

If yes, at what age did this condition begin? _____

OHA 0074 (1/18)

Appendix B. List of DHS/OHA and Shared Services data sets: Level of control and how data is collected

Agency	Data set/data system	Notes; control/how data is collected
OHA	Oregon ONE system (OHP)	Compliant; will be replaced by IE
OHA	Mental Health Statistics Improvement Program Survey for Adults	Compliant
OHA	Youth Services Survey	Compliant
Shared	Decision Support/Surveillance & Utilization Review System	Compliant
Shared	Integrated Client Services Data Warehouse (ICS)	Compliant
DHS	Caseworker Automated Processing Interface (CAPI)	
DHS	Client Process Monitoring System (CPMS)	
DHS	Employment-Related Day Care	
DHS	Food Stamp Management Information System (FSMIS)	Will be replaced by or linked to IE
DHS	Parts of Client Maintenance System (CM)	
DHS	Refugee Administration System	
DHS	Supplemental Nutrition Assistance Program	
DHS	Temporary Assistance for Needy Families	
OHA	Student Wellness Survey	Ends 2018
OHA	Oregon Healthy Teens (OHT) Survey — 11th Grade	Ends 2019
OHA	Oregon Healthy Teens (OHT) Survey — 8th Grade	Ends 2019
DHS	Alliance Working for Antibiotic Resistance Education — Oregon Rehabilitation Case Automation (ORCA)	High control/direct
DHS	Client Index System (CI)	Low control/both
DHS	Client Maintenance System (CM)	Low control/direct
DHS	Client Process Monitoring System (CPMS)	High control/direct
DHS	Oregon Automated Computer Capture & Storage System (ACCESS)	Medium control/direct
DHS	OR-Kids Statewide Automatic Child Welfare Information System	Medium control/direct
OHA	211 info (SafeNet)	High control/indirect
OHA	ALERT Immunization Information System	Low control/indirect
OHA	All-Payer All-Claims (APAC)	Medium control/both
OHA	ASPEN/Minimum Data Set	Low control/indirect
OHA	Breast and Cervical Cancer Program/Wisewoman/ScreenWise	High control/indirect
OHA	Behavioral Risk Factor Surveillance System	High control/direct
OHA	Birth Anomalies Registry (BAR;linked data sets)	Low control/indirect
OHA	Birth Certificate (Vital Records)	Low control/indirect
OHA	CAREAssist	High control/direct
OHA	Consumer Assessment of Health Plans & Systems Survey	High control/direct
OHA	Cuidate Entry & Exit Surveys	High control/direct

Agency	Data set/data system	Notes; control/how data is collected
OHA	Death Certificate (Vital Records)	Low control/indirect
OHA	Death with Dignity	Low control/indirect
OHA	Developing Equity Leadership through Training and Action respondents	High control/direct
OHA	Dental Sealant Program	High control/indirect
OHA	Dissolution of Domestic Partnership	Low control/indirect
OHA	Divorce	Low control/indirect
OHA	Early Hearing Detection & Intervention (EHDI)	Low control/indirect
OHA	Electronic Surveillance System — Early Notification of Community-based Epidemics	Low control/indirect
OHA	eLite	Need to assess
OHA	Environmental Public Health Tracking	Low control/indirect
OHA	Fetal Death	Low control/indirect
OHA	Genetic Infor System(Genls)	Low control/direct
OHA	Health Care Interpreter	High control/direct
OHA	Health Care Provider Survey Tracking System	High control/direct
OHA	Health Licensing Office data sets	Medium control/direct
OHA	Health Professional Shortage Areas & Medically Underserved Areas	Medium control/direct
OHA	Healthcare Assoc. Infections Data — Natl Healthcare Safety Network	Low control/indirect
OHA	Healthcare Workforce Database	Medium control/direct
OHA	Induced Termination of Pregnancy	Low control/indirect
OHA	Integrated Youth Survey (replaces OHT & Student Wellness in 2020)	High control/direct
OHA	Lead Poisoning Database	Low control/indirect
OHA	Licensing for EMS Providers & Ambulance Agencies	High control/direct
OHA	LIMS — Neometrics	Low control/indirect
OHA	LIMS — Orchard	Low control/indirect
OHA	Marriage	Low control/indirect
OHA	Matched Infant Death (linked data sets)	Low control/indirect
OHA	Measures & Outcomes Tracking System (MOTS)	Medium control/both
OHA	Medical Monitoring Project	Medium control/direct
OHA	Newborn Screening	Low control/indirect
OHA	OR Acute Care Hospital Inpatient Discharge Data set	Low control/indirect
OHA	OR EMS Information System	Low control/indirect
OHA	OR Health Insurance Survey (OHIS)	High control/direct
OHA	OR Medical Marijuana Registry	High control/direct
OHA	OR Patient Resident Care System	Low control/indirect
OHA	OR Pub Health Epidemiology User System (Orpheus)	Low control/indirect

Agency	Data set/data system	Notes; control/how data is collected
OHA	OR Registered Domestic Partnership	Low control/indirect
OHA	OR State Cancer Registry	Low control/indirect
OHA	OR Trauma Registry	Low control/indirect
OHA	OR Violent Death Reporting System	Low control/direct
OHA	Oral Health Surveillance System (linked)	Low control/indirect
OHA	Oregon Children's Health Care	Low control/indirect
OHA	Pesticide Exposure Safety & Tracking (PEST)	Low control/indirect
OHA	PHD Interns/Volunteers	High control/direct
OHA	Pregnancy Risk Assess. Monitoring System (Follow-Up Survey/PRAMS 2)	High control/direct
OHA	Pregnancy Risk Assess. Monitoring System(PRAMS)	High control/direct
OHA	Prescription Drug Monitoring Program	Low control/indirect
OHA	Private Insurance Carrier & Oregon Workers Comp Division	Low control/indirect
OHA	Regional Health Equity Coalition	High control/direct
OHA	ReproHealth — Title X & CCare	High control/indirect
OHA	SBHC Encounter Database	Medium control/indirect
OHA	SBHC Patient Satisfaction Survey	High control/direct
OHA	SMILE Survey (Oral Health)	Medium control/direct
OHA	State Emergency Registry of Volunteers in Oregon (SERV OR)	High control/direct
OHA	Statewide EMS Pre-hospital Care Data System	Medium control/indirect
OHA	Survey of Oregon Young Adults	High control/direct
OHA	Targeted Populations & General Public Survey Tracking System	High control/direct
OHA	Traditional Health Worker Registry	High control/direct
OHA	Women Infant Children (WIC) Data System (TWIST)	High control/indirect; will be linked to IE
Shared	Department of Administrative Services/Human Resources - Workday	High control/direct
Shared	Adult Abuse Database (OAAP)	High control/indirect
Shared	DHS Volunteer Database (Shared-includes OHA)	High control/direct
Shared	OR ACCESS Case Management System	High control/direct
Shared	Public Employees' Benefit Board/Oregon Education Benefit Board Claims	High control/direct
Shared	Public Employees' Benefit Board/Oregon Education Benefit Board Enrollment	High control/direct

Notes. High/med/low control refers to the extent DHS/OHA/Shared staff have in modifying the data set. Direct/Indirect refers to how the data is collected; direct = directly by staff, indirect = by external partners. This information is provided if the data set is not currently in full compliance with the REALD.

Appendix C: OHA data sets (excluding ONE/MMIS) making progress to comply with REALD

Data set name	Type of data	Typology: control and how the data is collected	Number of questions/categories					
			Racial/ethnicity		Language		Disability	
			2014	2016/17	2014	2016/17	2014	2016/17
211 info (SafeNet)	Consumer Based	High control/indirect	2	33	1	3	0	2
CAREAssist	Consumer-Based	High control/direct	NA	0	NA	5	NA	0
DELTA respondents	Investigative (Eval)	High control/direct	NA	34	NA	0	NA	7
DSSURS (OHP/MMIS)	Consumer-Based	High control/direct	2	34	2	6	0	13
Medical Monitoring Project	Invest/Surveillance	Medium control/direct	2	2	1	1	NA	7
MHSIPS (link to OHP)	Survey	High control/direct	2	34	0	6	0	13
Oregon Healthy Teens Survey — 11th Grade	Survey	High control/direct	0	0	0	0	2	6
Regional Health Equity Coalition	Investigative (Eval)	High control/direct	NA	34	NA	4	NA	7
WIC Data System (TWIST)	Invest/Surveillance	High control/indirect	0	0	5	5	0	0
Youth Services Survey (link to OHP)	Survey	High control/direct	2	34	0	6	0	13

Notes. DSSURS = Decision Support Surveillance & Utilization Review System; MHSIPS = Mental Health Statistics Improvement Program Survey (for adults).

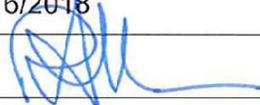
NA = not assessed or a new data set; control refers to level of control OHA staff have on making changes to the data collection instrument; the degree of control does not depend on the availability of sufficient resources; direct means that OHA or OHA contracted data vendor collects the demographic data directly from individuals; Indirect means that the demographic data from individuals is collected by external partners.

Appendix D: OHA REALD Implementation Policy

OFFICE OF EQUITY AND INCLUSION



Operational Policy

Policy title:	Implementation of Race, Ethnicity, Language, Disability (REALD) and ACA 1557 Data Collection Standards		
Policy number:			
Original date:	7/16/2018	Last update:	7/16/2018
Approved:			

Purpose

The purpose of this policy is to direct and ensure that the implementation of REALD data collection standards, analysis and reporting, is managed in a manner that is consistent, efficient, timely and in compliance with HB 2134, Oregon Administrative Rules (OARs) 943-070-0000 thru 943-070-007 and agency resources. The significance of the REALD standards is to recognize diverse identities, respect how people self-identify, and address health inequities with accurate and disaggregated data. In addition to the REALD standards, this policy also includes a process for developing standards for gender identity and sexual orientation per ACA Rule 1557.

Description

This policy and the corresponding resource guide ensure the implementation of REALD data collection standards, analysis and reporting in a manner that is consistent, efficient, timely and in compliance with Oregon Administrative Rules (943-070-0000 thru 943-070-007) and agency resources. This policy also includes a process for developing standards for gender identity and sexual orientation per ACA Rule 1557.

Applicability

This policy applies to all OHA programs and activities, staff including employees, volunteers, trainees and interns as well as contractors and subcontractors, who collect and record or report any demographic data through any means, such as sex, gender identity, age, race, income, ethnicity, disability, or language.

As keepers of the public trust, all agency employees have a responsibility to comply with state and agency policies, administrative rule, and state and federal law. The agency takes this responsibility seriously and failure to fulfill this responsibility is not treated lightly. Employees who fail to comply with state or agency policy, administrative rule, or state and federal law may face progressive discipline, up to and including dismissal from state service.

Definitions

For the purpose of this policy, the following definitions apply:

1. "Control" refers to the level of control OHA staff have on making changes to the data collection instrument; the degree of control does not depend on the availability of sufficient resources.
2. "Directly" means that OHA or OHA contracted data vendor collects the demographic data directly from individuals.
3. "Indirectly" means that the demographic data from individuals is collected by external partners.

Policy

1. All new data systems for collecting individual level demographic information shall be fully compliant with the REALD standards before going online.
2. Existing data systems collecting demographic data shall be compliant with the REALD standards as specified in Table 1.
3. Prioritized datasets will follow the compliance schedule designated in Table 2 based upon degree of control factors outlined in the table.
4. Non-prioritized datasets will follow the compliance schedule designated in Table 3 based upon degree of control factors outlined in the table.
5. Programs with data systems not currently in full REALD compliance shall complete a work plan for compliance and complete an online assessment survey, considering routine agency planning, budgeting, resources, and data collection cycles. The work plan shall be completed as specified in Table 1.
 - a. For datasets in which there is a **medium to high** degree of control by OHA and the data is collected **directly** by OHA or contracted OHA data vendor:
 - A. Within 3 months of passage of policy for **prioritized** data sets
 - B. Within 6 months of passage of policy for all other datasets.
 - b. For all other datasets:
 - A. Within 12 months of passage of policy for **prioritized** data sets
 - B. Within 24 months of passage of policy for all other datasets.
6. Workplans shall be completed following the guidance in the REALD Implementation Guide. A sample work plan is also in the Implementation Guide. Work plans shall reflect an actionable plan with timelines detailing how the program shall achieve compliance with the REALD standards.
 - a. For existing data sets *that rely on data collected indirectly by external partners*, in addition to the key elements listed in the sample work plan, the work plan shall include an **assessment** containing the following elements:
 - A. Required system level changes;
 - B. Resources needed to bring the data system into compliance;
 - C. The need for data agreements or contracts with subcontractors and external partners; and
 - D. Estimated timelines for full compliance with the REALD standards.
 - b. Work plans shall be submitted to the Office of Equity and Inclusion (OEI) Equity & Inclusion Policy/REALD Data Analyst containing the key elements listed in the sample work plan.
 - c. To help with accountability and tracking of REALD compliance, the OEI director in consultation with the OEI Equity and Inclusion Data Analyst shall approve all work plans.
7. The Office of Equity and Inclusion (OEI) Division shall convene a REALD Governance Committee made up of a representative from each OHA division, a representative from the Health Equity Committee, and three external stakeholders with general knowledge of using data to advance health equity. The committee may invite other stakeholders to provide consultation on specific data issues as needed. The committee shall:
 - a. Include at least one individual in each of the following groups: an individual with disability, a member of a community of color, and a person from an immigrant or refugee community.

- b. Advise on exemptions, modifications to REALD data categories and questions, implementation progress, and other issues that come up requiring decisions by the OHA director or the OEI Director.
 - c. Review extensions granted by the Agency.
 - d. Meet at least three times a year.
8. The OHA director, or a designee, in consultation with the OEI Director and the OEI Equity and Inclusion Data Analyst may grant extensions for implementation on a case-by-case basis when:
- a. A contract requires a program conducting work to use defined data collection protocols, instruments, algorithms, or databases that specifically prohibit modification.
 - b. An external entity provides the data used by the program and is not currently obligated by contract, legal mandate or a memorandum of understanding to collect the REALD minimum data elements.
 - c. A researcher is concerned about reporting using the REALD categories because of statistical unreliability in the data, small sample sizes, or privacy concerns. In this case the researcher shall:
 - A. Consult with the State Epidemiologist or Office of Health Analytics Director as appropriate. Recommendations may include aggregation of the demographic subgroup or report separately.
 - B. Demonstrate an attempt to address challenges or alternative ways to address challenges such as oversampling.
 - C. Notify the OEI Equity and Inclusion Analyst by email documenting the consultation and rationale, for review by the REALD governance committee, and submission to the OHA director, or a designee, in consultation with the OEI Director for approval.
9. The data standards represent minimum standards and do not limit the collection of additional necessary data.
- a. Data collection systems such as surveys that are not client or member-based shall use the language questions listed in the Figure 1 designation of the references to identify and address disparities.
 - b. If program staff thinks the REALD categories and question are not appropriate under particular circumstances, or the questions and categories needs to be modified, the program staff shall consult with the OEI Equity and Inclusion Analyst for review of suggested modifications; changes to the standards and exemptions need to be presented to the REALD Governance Committee (see 7b above).
 - c. REALD categories and questions shall not be omitted due to issues inherent in disparity research, including but not limited to limitations in data systems such as the number of fields or comparability of categories among systems; the space on paper or electronic collection forms; or privacy concerns.
10. OHA programs shall use the disaggregated REALD data categories as much as possible when generating existing reports and publicly available data.
11. The collection of data shall be sensitive to constituent concerns about potential misuse or abuse.
- a. Reporting shall not violate the privacy of individuals represented in the dataset.
 - b. Information on the validity and reliability of the data shall be included in reporting, if available.
12. OEI shall provide biannual dashboard tracking progress on work plans and compliance to OHA leadership and program managers overseeing datasets with demographics.
13. In odd numbered years, OEI shall submit to OHA leadership and legislators the results of the annual survey assessing datasets or data systems not yet in full compliance with the REALD data collection standards.
14. No later than September 30, 2018, OEI shall begin developing recommendations for data collection standards through a community engagement process that includes internal and external

stakeholders, and centers on those reflected in, and most affected by, the gender identity and sexual orientation data collection standards.

References

Figure 1. Language Questions for Non-Client Based Data Systems

1. Do you speak a language other than English at home? (5 years old or older) (Response categories: Yes, No, Don't know or Unknown, Don't want to say or Decline to answer).
- For persons speaking a language other than English (answering yes to A above):
2. What is this language? (5 years old or older) (Response categories shall include American Sign Language, Other sign language, Don't know or Unknown, Don't want to say or Decline to answer).
3. What language do you feel most comfortable speaking with your doctor or nurse? (5 years old or older) (Response categories shall include American Sign Language, Other sign language, Don't know or Unknown, Don't want to say or Decline to answer).
4. In which language would you feel most comfortable reading medical or health care instructions? (15 years old or older) (Response categories shall include Don't know or Unknown, Don't want to say or Decline to answer).
5. How well do you speak English? (5 years old or older) (Response categories: Very Well, Well, Not Well, Not at all, Don't know or Unknown, Don't want to say or Decline to answer).

Table 1. Workplan and Compliance Timelines from Date of Passage of Implementation Policy

	Prioritized Dataset / Data System?	
	Yes	No
Medium to high control & data is collected directly by OHA or OHA data vendor	Workplans: 3 months	Workplans: 6 months
	Compliance: 18 months	Compliance: 36 months
Low control & data is collected directly by external partners	Work plans: 12 months	Work plans: 24 months
Medium to high control & data is collected indirectly by external partners	Compliance: 36 months	Compliance: 48 months
Low control & data is collected indirectly by external partners	Workplans: 12 months	Workplans: 24 months
	Compliance: To be determined from the workplan assessment process.	

Table 2. Prioritized OHA/Shared Datasets with Timelines for Work plans and Compliance

#	Name of OHA or Shared Dataset	Level of Control on Changes to Dataset	Data Collected (how)	Months Due upon Passage of Policy	
				Workplan	Compliance
1	Behavioral Risk Factor Surveillance System	High	Direct	3	18
2	CAREAssist	High	Direct	3	18
3	Integrated Youth Survey *	High	Direct	3	18
4	Mental Health Statistics Improvement Program Survey	High	Direct	3	18
5	Pregnancy Risk Assess. Monitoring System 1	High	Direct	3	18
6	Pregnancy Risk Assess. Monitoring System 2	High	Direct	3	18
7	Targeted Populations & General Public Survey Tracking	High	Direct	3	18
8	Measures & Outcomes Tracking System	High (OHP/ICS)	Direct	3	18
9	OR Violent Death Reporting System*	Low	Direct	12	36
10	All-payer all-claims database (APAC)	Low/High (OHP)	Both	12	36
11	Ahlers/ScreenWise - WISEWOMAN & BCC	High	Indirect	12	36
12	Oral Dental Sealant Program*	High	Indirect	12	36
13	Women Infant Children Data System (TWIST)	High	Indirect	12	36

14	Birth certificate	Low	Indirect	12	TBD
15	Electronic Surveil.System Early Notif.of Com. Based Epidemics	Low	Indirect	12	TBD
16	Fetal Death	Low	Indirect	12	TBD
17	Lead Poisoning Database	Low	Indirect	12	TBD
18	Matched Infant Death (linked datasets)	Low	Indirect	12	TBD
19	OR Patient Resident Care System	Low	Indirect	12	TBD
20	Oregon Childrens' Health Care	Low	Indirect	12	TBD
21	Oregon Public Health Epidemiology User System	Low	Indirect	12	TBD

Note. Svy = Survey; OHP = Oregon Health Plan; ICS = Integrated Data Warehouse, TBD = to be determined from the workplan assessment process.

"Control" refers to the level of control OHA/DHS staff have on changes to data elements collected as well as how the data is collected; this estimation of control is subject to change with greater understanding of data system. The level of control is not dependent on resources or funding availability.

"Direct" indicates data collected directly from individuals by OHA staff (or vendors on contract with OHA to collect such data).

"Indirect" indicates that the data is collected indirectly by external partners.

"Both" refers to data collected directly by OHA/DHS (such as OHP), as well as indirectly from other providers.

* Several changes in datasets prompted changes to the list: 1) the Adolescent Suicide Attempt Data System (ASADS) is no longer used; instead, PHD is using the OR Violent Death Reporting System, 2) the Oral Dental Sealant Program is prioritized instead of the SMILE Survey, and 3) The Integrated Youth Survey was added as it will eventually replace Oregon Health Teen (OHT) surveys and the Student Wellness Survey when launched in 2020. Due to the end dates of the OHT survey (2019) and the SWS survey (2018), these two datasets are no long prioritized.

Table 3. Non-prioritized OHA/Shared Datasets with Timelines for Workplan and Compliance

#	Name of OHA or Shared Dataset	Level of Control on Changes to Dataset by OHA	Data Collected (how)	Months Due upon Passage of Policy	
				Workplan	Compliance
1	BRFSS Survey of State/School Employees	High	Direct	6	36
2	Client Process Monitoring System (CPMS)	High	Direct	6	36
3	Consumer Assessment of Health Plans & Systems Svy	High	Direct	6	36
4	Cuidate Entry & Exit Surveys	High	Direct	6	36
5	DAS/HR - Workday	High	Direct	6	36
6	DELTA respondents	High	Direct	6	36
7	DHS Volunteer Database (Shared-includes OHA)	High	Direct	6	36
8	Health Care Interpreter	High	Direct	6	36
9	Health Care Provider Survey Tracking System	High	Direct	6	36
10	Licensing for EMS Providers & Ambulance Agencies	High	Direct	6	36
11	OR ACCESS Case Mgmt System	High	Direct	6	36
12	OR Health Insurance Survey (OHIS)	High	Direct	6	36
13	OR Medical Marijuana Registry	High	Direct	6	36
14	PEBB/OEBB Claims	High	Direct	6	36
15	PEBB/OEBB Enrollment	High	Direct	6	36
16	PHD Interns/Volunteers	High	Direct	6	36
17	Regional Health Equity Coalition	High	Direct	6	36
18	SBHC Patient Satisfaction Survey	High	Direct	6	36
19	State Emergency Registry of Volunteers in Oregon	High	Direct	6	36
20	Survey of Oregon Young Adults	High	Direct	6	36
21	Traditional Health Worker Registry	High	Direct	6	36
22	Youth Services Survey	High	Direct	6	36
23	Health Licensing Office datasets	Medium	Direct	6	36
24	Health Professional Shortage Areas & Medically Underserved Areas	Medium	Direct	6	36
25	Healthcare Workforce Database	Medium	Direct	6	36
26	Medical Monitoring Project	Medium	Direct	6	36
27	SMILE Survey (Oral Health)	Medium	Direct	6	36
28	Workday (HR database)	Medium	Direct	6	36
29	Genetic Infor System (Genls)	Low	Direct	24	48
30	211 info (SafeNet)	High	Indirect	24	48
31	Adult Abuse Database (OAAPI)	High	Indirect	24	48
32	ReproHealth-Title X & CCare	High	Indirect	24	48
33	SBHC Encounter Database	Medium	Indirect	24	48
34	Statewide EMS Pre-Hospital Care Data System	Medium	Indirect	24	48

Table 3. Continued

#	Name of OHA or Shared Dataset	Level of Control on Changes to Dataset by OHA	Data Collected (how)	Months Due upon Passage of Policy	
				Workplan	Compliance
35	ALERT Immunization Information System	Low	Indirect	24	TBD
36	ASPEN/MDS	Low	Indirect	24	TBD
37	Death Certificate	Low	Indirect	24	TBD
38	Death with Dignity	Low	Indirect	24	TBD
39	Dissolution of Domestic Partnership	Low	Indirect	24	TBD
40	Divorce	Low	Indirect	24	TBD
41	Early Hearing Detection & Intervention(EHDI)	Low	Indirect	24	TBD
42	Environmental Public Health Tracking	Low	Indirect	24	TBD
43	Healthcare Assoc. Infections Data from Natl Healthcare Safety Network	Low	Indirect	24	TBD
44	Induced Termination of Pregnancy	Low	Indirect	24	TBD
45	LIMS-Neometrics	Low	Indirect	24	TBD
46	LIMS-Orchard	Low	Indirect	24	TBD
47	Marriage	Low	Indirect	24	TBD
48	Newborn Screening	Low	Indirect	24	TBD
49	OR Acute Care Hospital Inpatient Discharge Dataset	Low	Indirect	24	TBD
50	OR EMS Information System	Low	Indirect	24	TBD
51	OR Registered Domestic Partnership	Low	Indirect	24	TBD
52	OR State Cancer Registry	Low	Indirect	24	TBD
53	OR Trauma Registry	Low	Indirect	24	TBD
54	Outpatient & Free-Standing Ambulatory Surgical Centers Discharge Data	Low	Indirect	24	TBD
55	Pesticide Exposure Safety & Tracking (PEST)	Low	Indirect	24	TBD
56	Prescription Drug Monitoring Program	Low	Indirect	24	TBD
57	Private Insurance Carrier & Ore Workers Comp Div .	Low	Indirect	24	TBD

Note. This Table does not include elite nor the Spider dataset due to insufficient information about these two datasets. TBD = to be estimated during the course of the assessment workplan.

“Control” refers to the level of control OHA/DHS staff have on changes to data elements collected as well as how the data is collected; this estimation of control is subject to change with greater understanding of data system. The level of control is not dependent on resources or funding availability.

“Direct” indicates data collected directly from individuals by OHA staff (or vendors on contract with OHA to collect such data). “Indirect” indicates that the data is collected indirectly by external partners.

Forms referenced

Insert forms here

Related policies

HB 2134: <https://olis.leg.state.or.us/liz/2013R1/Downloads/MeasureDocument/HB2134>

REALD OARS http://arcweb.sos.state.or.us/pages/rules/oars_900/oar_943/943_070.html

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Policy history

Insert date policy was established
Insert each revision date

Keywords

Race, racial, ethnic, ethnicity, language, disability, functional limitations, data collection standards, multiracial, demographics

Keywords should be designed to help individuals locate this policy when they need it.

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