


Operational Policy

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| 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 Mmgt 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 (GenIs) | 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.

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

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