

Race, Ethnicity, Language, & Disability (REALD)

Implementation Guide



Acknowledgments

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Introduction

The purpose of this guide is to provide in-depth information to facilitate implementation of the Race, Ethnicity, Language, and Disability (REALD) demographic data collection standards. This guide also includes information to support analysis and reporting of REALD data.

Overview of the guide

Below is a brief overview of each section of this guide. Many sections includes links to additional resources. A glossary of terms and acronyms used in this guide follow.

1. REALD and what it means for Oregon:

This section covers:

- Why REALD matters, what it is, and the purpose of REALD
- Who REALD applies to, and
- A history of how and why REALD was developed.

This section explains the benefits of increased details in the standards. This section also provides an overview of foundational concepts underlying the REALD standards. This includes:

- Health equity
- Inequities, inequities, and
- Social determinants of equity and health.

2. Understanding the REALD categories and questions:

This section begins with an overview of REALD categories and questions. There are detailed FAQs for:

- Race and ethnicity
- Language, and
- Disability.

This section also provides indepth examples of subgroup differences by racial and ethnic identity categories.

3. REALD Implementation Policy and work plan:

This section reviews key REALD Implementation Policy and work plan requirements. It describes how older datasets are being brought into compliance, following prioritization. There is a work plan template, checklist for data collection tools, and a flowchart of the implementation process. There is an explanation of the analyses and reporting requirements of the REALD Implementation Policy.

4. Data collection:

This section includes key points and concepts about

- REALD data collection
- Accessibility requirements
- Guidelines for designing and formatting questions, as well as information on messaging, and how to “ask the questions,” and,
- Ways to collect, map and store REALD data.

Additional information on training needs, as well as other resources and tools to aid in data collection are also provided.

5. Data quality, analyses and reporting:

Suggestions for data quality checks are in this section. There are also guidelines for analyses and reporting such as:

- Intermediate aggregation
- Addressing challenges associated with small samples (or subgroups)
- Reporting alone or in combination, and alone or in *any* combination
- Using the primary race category and imputation when needed
- Estimating granular racial and ethnic denominators using American Community Survey Public Use Microdata Sample (PUMS)
- Considerations for disability-specific analyses, and
- Intersectionality using REALD as an analytic tool.

6. Data collection resources:

This section includes information and links to:

- REALD templates
- IDEAS decision tool, and
- Other internal resources.

7. REALD and communities (community engagement):

The goal of REALD data is to identify and address health inequities. This section includes:

- Guidelines for representing diverse populations during data collection
- Responding to data requests from community organizations
- Distributing data for communities to use, and
- Engaging communities when conducting research.

8. Community engagement resources:

This section highlights resources to help OHA staff engage with community partners equitably such as:

- Use of popular education to equalize power differences
- Community based participatory research principles, and
- Community Engagement Strategies Checklist.

9. References for researchers:

This section provides a list of comprehensive references by topic that may be of interest to researchers, such as:

- Documented health inequities
- Data collection strategies to address small sample size challenges, and
- Subgroup analyses.

Appendix A. Reliability and validity of the ACS disability questions

1. REALD and what it means for Oregon

Why race, ethnicity, language, and disability (REALD) demographic data collection matters

The collection REALD demographic data matters because certain groups of people experience avoidable health inequities. Everyone does not:

- Receive the same level of health care, and
- Have the same access to quality health care.

This results in avoidable differences in health outcomes.

Avoidable differences in health due to race, ethnicity, language, and disability have been clearly documented. However, we have not been able to fully address and eliminate these inequities. In order to accurately identify health inequities and subpopulations that may benefit from focused interventions, data collection with more granularity in race, ethnicity and language (Hasnain-Wynia et al., 2007; Institute of Medicine (IOM), 2003; Ulmer, McFadden, & Nerenz, 2009) is needed. Additionally, there is a need for data collection of disability as a demographic. This helps to fully identify and address avoidable health inequities experienced by people with disabilities (Krahn, Walker, & Correa-De-Araujo, 2015; Wisdom et al., 2010).

REALD matters as it reveals the diversity of the people living in Oregon. Oregon is becoming more diverse:

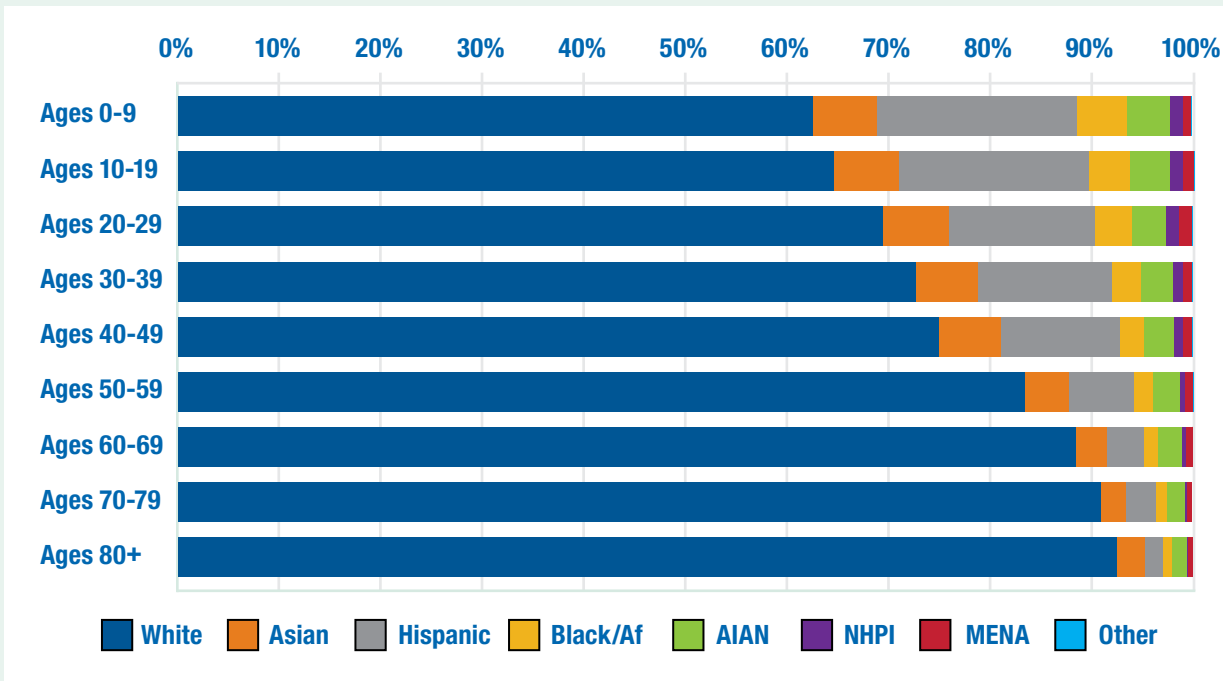
- About 35 percent of those under age 15 in Oregon are young people of color (Figure 1).
- The percentage of those under age 45 who speak another language (19.1 to 21 percent) is nearly twice that of those age 45 or older (6.8 to 11 percent) (Figure 2).

Oregon is also diverse with respect to people with disabilities. The percent of people with disabilities in Oregon ranges from 14.7 percent* to 25.8 percent† depending on the survey (Figure 3).

* U.S. Census Bureau, American Community Survey (2013-2017 five-year estimates). excluded non-civilians and people living in institutions. percents are weighted.

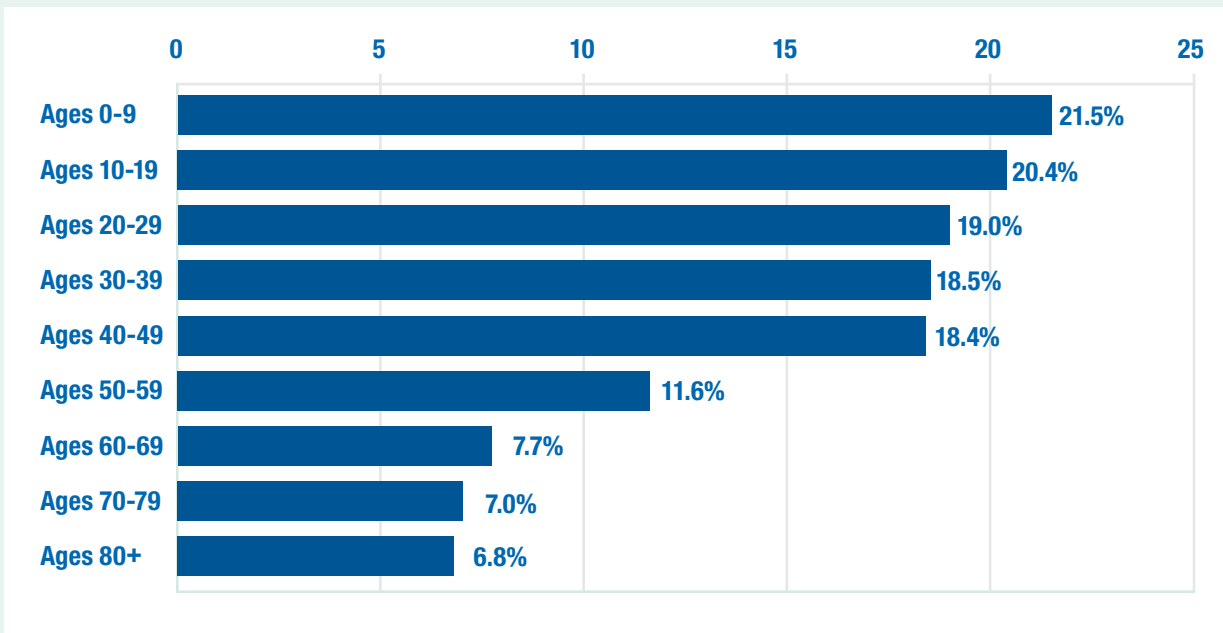
† 2016 Behavioral Risk Factor Surveillance Survey

Figure 1: Oregon’s racial and ethnic diversity by age group (percentage)



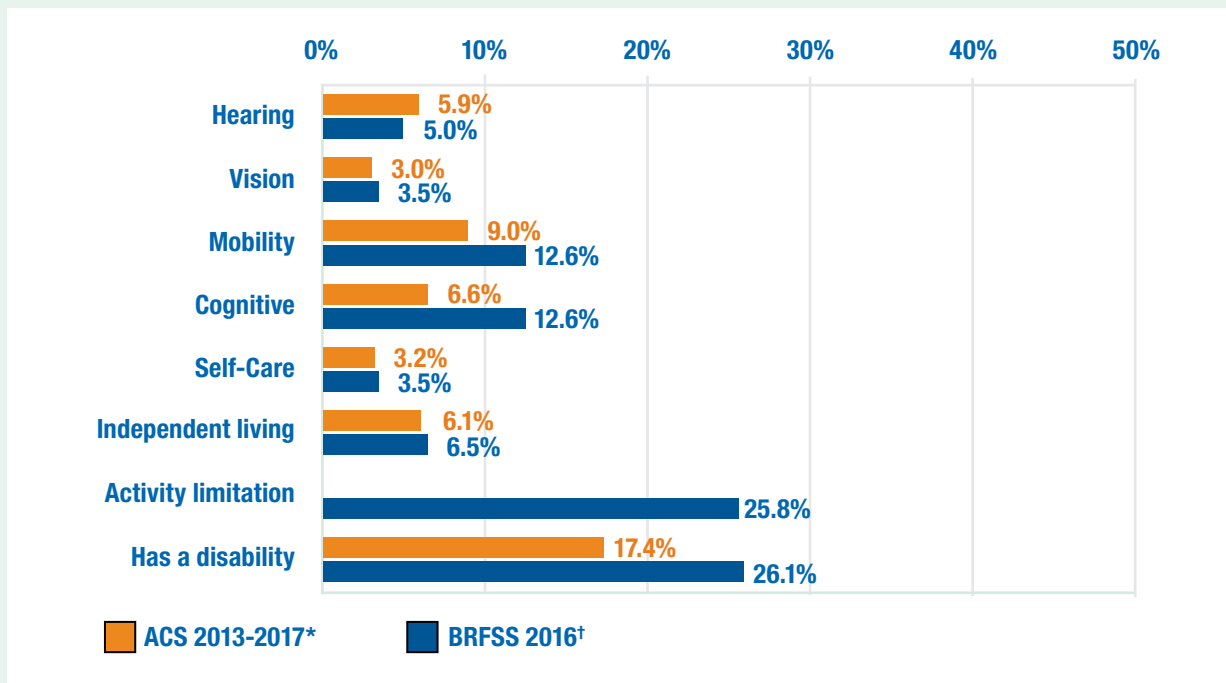
Source: U.S. Census Bureau, American Community Survey (2013-17 5- year PUMS data). The “most identify/rarest” group methodology was used to impute a primary race when there were two or more races and/or ethnicities reported by the Census. Weighted percentages.

Figure 2: Percent of people in Oregon who speak another language other than English at home



Source: U.S. Census Bureau, American Community Survey (2013-17 5- year PUMS data). Excluded children under age 5.

Figure 3: People with disabilities in Oregon by two federal surveys (percentage)



Note. Weighted percentages pertain to Oregonians age 18 and over.

* ACS = American Community Survey (2013-2017 5-year PUMS data). The ACS does not include the activity limitation question.

† BRFSS = Behavioral Risk Factor Surveillance Survey.

Overall percentages are based on whether a person answered “yes” to 1 or more disability questions. Overall, among Oregonians age 18 and over, ACS figures indicate that 17.4% of Oregonians has a disability compared to 26.1% using BRFSS 2016 figures. The differences between the ACS and BRFSS estimates may be largely due to sampling design and nonresponse bias (Gettens, 2015, p1.)

What is REALD?

REALD is an effort to increase and standardize race, ethnicity, language, and disability data collection across the Department of Human Services (DHS) and the Oregon Health Authority (OHA). Data collection was advanced through the passage of House Bill (HB) 2134 during the 2013 legislative session and Oregon Administrative Rules (OARs) [943-070-0000 through 943-070-0070](#).

REALD includes a set of standardized data categories and questions. REALD data must be collected in OHA and DHS datasets and by contractors of OHA and DHS.

It is beneficial to collect race, ethnicity, language, and disability demographic data. Some of the many reasons are to:

- Meet federal and state reporting needs
- Understand better the different populations we work with or serve

- Identify and address social and health inequities
- Guide the development of culturally specific and accessible services, and
- Guide equitable allocation of resources to address inequities.

Health equity

To understand how REALD helps address health and social inequities, we first need to understand what we mean by “health equity.” There are many factors that influence health:

- Where we are born
- Our experiences growing up, and
- Where we live, learn, work and play.

Experiences of our parents, grandparents and ancestors also affect our health and well-being. Health equity is achieved when there are no avoidable differences in health between and within groups of people. Some factors such as lack of access to health care or discrimination negatively influence health and create inequities that are avoidable. To promote the health of all people we must uproot the causes of health inequity.

Achieving health equity means to assure conditions for the highest possible level of health for all people. To achieve health equity we must:

- Value all individuals and populations equally
- Recognize and rectify historical and contemporary injustices, and
- Provide resources based on need.

Health inequities will be eliminated when health equity is achieved.

Health inequities are “differences in health that are not only unnecessary and avoidable, but in addition, are considered unfair and unjust” (Whitehead, 1992, p. 433). They are structural health differences that adversely affect groups of people who systematically experience greater economic, social, or environmental obstacles to health based on:

- Racial or ethnic group
- Religion
- Socioeconomic-status
- Gender
- Age
- Mental health
- Cognitive, sensory, or physical disability
- Sexual orientation or gender identity
- Geographic location, or
- Other characteristics historically linked to discrimination or exclusion.

Health inequities are the metric used to measure progress toward achieving health equity.

Social determinants of equity and health

To address health inequities, we need to address the systems of power (i.e. the economic system) that affect the distribution of social contexts. **Social determinants of equity** (Jones, 2014) focuses on the **structural** determinants and systems of power. **Social determinants of health** focuses on contexts that influence our behaviors. In other words, conditions in which people are born, grow up and live in. It includes healthcare, as well as things we rarely think of in relation to health, such as:

- Historical oppression
- Trauma
- Education
- Food supply
- Housing, and
- Transportation

These contexts can make it easier (or harder) to be healthy and safe. People are more likely to experience health inequities when they have been exposed to discrimination due to their race, disability, gender, English proficiency, or other demographic characteristics (Darity, 2003; Institute of Medicine (IOM), 2003; Link & Phelan, 1995; Link & Phelan, 2006; Mays, Cochran & Barnes, 2007; Nazroo, 2003; Williams & Mohammed, 2009).

Data collection standards such as those used in REALD bring recognition and visibility to everyone. They give us the ability to identify and address health inequities. For a short video (three minutes) on health equity click [here](#)

Why do we have so many questions and categories in REALD?

In order to accurately identify health inequities and subpopulations that may benefit from focused interventions, there is a need for more granularity in race, ethnicity and language. This is clearly articulated by the authors of an Institute of Medicine report based upon an extensive literature review, who state that the federal [Office of Management and Budget \(OMB\)](#) categories:

“mask important inequities in health and health care. More discrete ethnicity groups, based on ancestry, differ in the extent of risk factors, degree of health problems, quality of care received, and outcomes of care. More granular ethnicity data could inform the development and targeting of interventions to ameliorate inequities in health care that contribute to poorer health”

(Ulmer et al., 2009, p. 31).

We also need additional questions to identify people with disabilities (Hasnain-Wynia et al., 2007; Institute of Medicine (IOM), 2003; Ulmer et al., 2009).

Oregon is going beyond the federal [OMB standards](#). By collecting granular race, ethnicity, language, and disability data, we will be able to:

- Identify specific subgroups who experience inequities
- Determine the magnitude of inequities, and
- Find out how they are changing over time.

Strong data tracking of these inequities are imperative to:

- Support efforts to understand the causes
- Design and implement focused responses, and
- Measure progress over time (Aligning Forces for Quality, 2010; Hasnain-Wynia & Baker, 2006; Lurie & Fremont, 2006; Moy, Arispe, Holmes, & Andrews, 2005; U.S. Department of Health and Human Services, 2011a, 2011b).

This information can then inform interventions and policy changes. REALD collects more thorough and granular data so inequities can be identified and then addressed.

We live in a data-driven society. Data is often needed to both identify and validate the existence of health inequities. Data is also extremely valuable to obtain support and funds to address issues. Social and health inequities should consider differences in lived experiences (e.g., culture, migration, histories, language, gender or sex, disability, etc.). We can use race, ethnicity, language and disability data collection standards to identify and address social and health inequities.

Assessing equity requires making comparisons between social groups with different levels of social advantage. In each setting, one should ask: “What are the key social groupings in this setting that define underlying social position and privilege?” (Braveman, 2003, p. 187).

Documenting racial and ethnic inequities and analyzing their causes is becoming increasingly complex (Hayes, Lukacs, & Schoendorf, 2008). There are dangers in aggregating data. Doing so can mask within-group differences such as with Asian Americans, Native Hawaiian and other Pacific Islander populations (Wong, Hosotani, & Her, 2012). Aggregation can support the “model minority myth” with respect to Asian Americans. This is the myth that all Asian groups experience academic and societal success and do not experience inequities (Nguyen, Chawla, Noone, & Srinivasan, 2014). Findings based on data that expand beyond OMB standards can greatly increase our knowledge about similarities and differences within subgroups. (See for example: Tyson, Castañeda, Porter, Quiroz, & Carrion, 2011).

Are other organizations recommending similar data collection standards?

In 2011, the U.S. Department of Health and Human Services (HHS) published [data collection standards](#) with greater granularity for race, ethnicity, sex, primary language, and disability for inclusion in federally-sponsored surveys (U.S. Department of Health and Human Services, 2011a, 2011b). Consequently, several large national surveys currently collect more data on race, ethnicity, sex, primary language, and disability status than required by the OMB.*

Further, a number of other entities develop more extensive data collective standards. See [here](#) for a comparison of some racial and ethnic categories used in different health systems in the United States.

Applicability: Who needs to collect REALD data?

HB 2134 passed in 2013 requires uniform standards for collection of REALD demographic data whenever any type of demographic data are collected. All of the following must comply with REALD standards:

- OHA and DHS programs and activities, and
- State contractors and subcontractors who collect, record, or report demographic data (such as gender, age, income, race, ethnicity or language).

For example:

- The *ONE application (OHP)* and *TWIST* (individual level Women, Infants and Children [WIC] data collected from local health departments) are both required to follow REALD data collection standards. This is because they both collect demographics from individuals such as race and language.
- The *School Health Profiles (Profiles) Survey* and the *Safe Drinking Water Information System* are examples of data systems *not* collecting individual level demographic information. Thus, there is no requirement to follow REALD data collection standards.

* Examples include the American Community Survey, National Health Interview Survey and the Current Population Survey.

History: How was REALD developed?

OHA and DHS already had a REAL (Race, Ethnicity and Language) policy in place before 2012. However, OHA and DHS did not collect the level of granularity of current REALD questions; nor was there standardized data collection for disability. As a result, communities led an effort to address OHA and DHS race, ethnicity, language and disability collection limitations. Starting in 2012, community organizations, particularly the Asian Pacific American Network of Oregon (APANO) and Oregon Health Equity Alliance (OHEA), led the efforts to collect granular data on race, ethnicity, language and disability. HB 2134, required DHS and OHA to develop a standard to collect REALD data with community stakeholders. These standards, finalized in 2014, were developed through many committee meetings with internal and external stakeholders and researchers. The standards are based on local, state, and national best practices.

REALD rule making process

REALD data collection standards were developed through an interactive and thorough process. The REAL HB2134 Subcommittee, which consisted of research analysts, program staff, and other staff from OHA and DHS, met regularly in 2013 to develop the standards. They compared questions from other large surveys to find commonalities among the surveys. For example, they assessed surveys from the Council on Quality of Care and Outcomes Research (QCOR) and the American Community Survey from the U.S. Census Bureau. The Rules Advisory Committee consisted of external stakeholders who also met regularly during this same time and reviewed drafts of questions. The REALD standards were finalized in the OARs in early 2014. The rules became final after a series of public hearings and opportunities for public comment.

Benefits of using REALD data

Standardizing the questions and categories greatly enhances our ability to identify and address inequities. We can use the data in the following ways without relying on assumptions or anecdotes:

- Develop parity reports.
- Identify avoidable inequities (e.g., access to services and health outcomes) between groups and within groups of people. With this information, REALD data can be used to:
 - » Determine who are most impacted by identified inequities
 - » Address identified inequities through policy and legislative efforts
 - » Make the case for additional resources and funds needed to effectively address avoidable inequities. For example, an accurate count of Iranian Americans can help this community secure funds, gain political influence, and conduct ethnic research (such as on demographic trends or economic and educational status) (Public Affairs Alliance of Iranian Americans., n.d.).
 - » Design culturally appropriate and accessible interventions at:
 - ◇ Individual
 - ◇ Community, and
 - ◇ Organizational level
 - » Monitor progress to reduce inequities over time.
- Determine who are being served or surveyed, which helps to:
 - » Ensure effective interpreter (spoken) and translation (written) services
 - » Develop culturally specific and accessible programs, services and materials (such as health education materials and survey tools), and
 - » Determine if certain groups of people are underserved based on parity reports.
- Determine if the workforce reflects the population being served by race, ethnicity, language and disability. This information can be used to:
 - » Determine the need for focused outreach and recruitment of members from underrepresented groups, and
 - » Develop staff cultural competency training.

“If you ask a different question, you will get a different answer. Standardizing the questions and categories allows a single data set to be comparable when collected by thousands of individuals across the state”

(K. Hampton, personal communication, September 2018).

- Develop intersectional reports that consider multiple identities or characteristics of groups by race, ethnicity, language and disability. For example, a community partner interested in providing services to refugees and immigrants with disabilities could request data about the number of refugees and immigrants with disabilities served by DHS or OHA. See [here](#) for an example an intersectional approach used to estimate the number of refugees and immigrants with disabilities in Oregon).
- Guide and facilitate **cross-sector collaboration** and **community engagement**.

The REALD data fills gaps in knowledge when applied in the ways listed above. Sharing this knowledge with public health, health care and community organizations can inform their work. This can improve health in the populations they serve. See Table 1 below for a summary of how REALD data can be used. OHA provides corresponding examples at each step.

Table 1: Using REALD to identify and address inequities among students with disabilities

Steps	Examples
Step 1: Detailed information on participant’s race, ethnicity, language and disability are collected.	Numerous data systems already collect data on many aspects of people’s lives and health. This includes surveys such as the Oregon Healthy Teens Survey. With REALD, systems collect more thorough data on race, ethnicity, language, and disability.
Step 2: With REALD data we will be able to link with other data collected (health conditions, health behaviors, etc.).	Granular data on Oregon Healthy Teens Survey for 11th graders in 2015 lets us look at how abuse data relates to disability. Data indicates students missing school in the past 30 days due to concerns for their safety at school was “especially pronounced among deaf and hard of hearing students and those with self-care, mobility, and independent living difficulties” (Oregon Health Authority, 2017).
Step 3: If we see inequities, focused analyses and interventions can address gaps.	Schools and community organizations can use data to better explore why deaf and hard of hearing students are more likely to miss school due to concerns for their safety. Attention can be given at the organization and individual levels. With better use of data, schools and community organizations can better address the problem of missing school due to concerns for the safety of students at school.

2. Understanding REALD categories and questions

This section provides a general overview of REALD standards. It starts with common key elements for all questions, followed by an in-depth explanation of the REALD categories (defined in OAR [943-070-0010](#)). Additional information about how to implement these categories is found in [section four](#).

REALD questions are available to use in a [pre-formatted template designed for paper-based data collection efforts \(OHA 0074\)](#). Translations are available for over 20 languages, in different versions. Dataset managers and other data collection staff can customize these templates to fit their specific needs. However, they cannot change the actual questions or categories. OHA staff can work with the Publications and Creative Services Office to customize for their purposes (e.g., include questions from other forms).

2014 REALD baseline report

An assessment of 55 OHA datasets that collect demographic information revealed the following:

- Only 24 percent ask open-ended race and ethnicity questions
- 45 percent collect some data on language, and
- 16 percent collect some data on disability
- None were REALD compliant.

The most recent REALD legislative report can be found [here](#).

Key REALD elements

All of the following must comply with REALD standards whenever demographic data are collected:

- OHA and DHS programs and activities
 - » This includes state contractors and subcontractors who collect, record, or report demographic data and provide such data to OHA and or DHS.
 - » Gender, age, income, race, ethnicity or language are examples of “demographic” data. If any demographic data are collected, then we are required to comply with REALD with respect to all REALD demographic data.

REALD data collection standards for race, ethnicity, language and disability represent **minimum standards**. The standards are not intended to limit collection of needed data. Standards were based on populations in Oregon. OARs [943-070-0000 through 943-070-0070](#) **requires all** REALD questions and categories be included in data collection that contains demographic data of any kind.

A key principle underlying REALD is that of **self-reporting**. OARs specify that the “Authority, Department, or Contractor shall not assume or judge ethnic and racial identity, preferred signed, written and spoken language, or disability without asking the individual” (OAR [943-070-0200\(3\)\(a\)](#)). Since the REALD data standards reflect identities, language preferences and functional limitations, self-reporting will typically provide the most accurate information (Bilheimer & Sisk, 2008; Hasnain-Wynia & Baker, 2006; Kressin, Bei-Hung, Hendricks, & Kazis, 2003; Schmidt et al., 2015; Ulmer et al., 2009).

It is also important to avoid making assumptions about the person based upon shared membership in a certain community.

“When an individual self-identifies as being from a certain population subgroup, it may also mean that the individual is more likely to have health beliefs, health care use patterns, and perspectives about the health care system that are common to that community”

(Hasnain-Wynia & Baker, 2006, p. 1509).

A person has the right to select one of the below options or to provide their information. Response or the lack of response to the REALD questions shall not affect eligibility for any service. There are two active “**nonresponse**” options that are different from “missing” responses. Nonresponse options are associated with all REALD questions:

- **Don’t know** (*Unknown*) is used when:
 - » The person or their caregiver is **unable** to provide an answer, or
 - » There is no available family member or caregiver to respond for the person.
- **Don’t want to answer** (*Decline to answer*) is used when the individual **actively chooses not** to provide their demographic information.

With active nonresponse options, it is hoped that the number of “missing” responses will be low.

General REALD FAQs

Do we always need to ask all questions?

Oregon Administrative Rules OARs [943-070-0000 through 943-070-0070](#) requires all REALD questions and categories be included in data collection. However, there may be cases where it does not make sense to ask some questions. For example, a question about the need for a sign language interpreter or alternate formats during a telephone-based surveillance survey may not make sense. In addition, accessibility needs should be addressed before the survey starts. However, there are [alternate language questions for non-service-based data systems](#). Refer to the REALD Implementation Policy for additional requirements and guidance.

Can we reformat or move questions around to improve response rates and meet accessibility needs?

Yes. REALD standards do not specify the order of REALD questions. Dataset managers can adjust the order of the sections to fit populations they serve. On the [REALD survey template](#) the question about alternate formats was placed before the race and ethnicity section. The rest of the language questions are on the second page. Clients, members or participants may be used to seeing questions about their race and ethnicity. Thus, they may feel more comfortable in answering those questions first, then moving to possibly less-familiar questions about language, followed by disability.

To ensure that REALD questions are accessible to all, data collectors should ask about the communication and other accessibility needs of the person before the survey is started. If the person indicates a need for alternate formats or prefers a written or spoken language other than English, a process can then be created to ensure the survey is fully accessible for that person.

What if it is not possible to include all the REALD questions and categories?

It would be very unusual to demonstrate that it is not possible to include all REALD questions and categories. But it may not be easy. OARs use the term “practicable” (possible). That is not always the same as “practical” (reasonable). In order to achieve health equity we must implement REALD fully. **If you want to make a change you must get approval from OHA’s Office of Equity & Inclusion (OEI).**

Why ask questions about subgroups if the numbers are too small to analyze?

Often, a group that experiences inequities is relatively small. Thus, the group does not have as much visibility. For this reason, REALD categories and questions shall not be omitted even if the size of a subgroup is thought to be so small that it will be

difficult to report the disaggregated data. Several strategies developed to address these types of challenges are outlined in [section five](#).

Are all datasets required to comply with the REALD data collection standards?

No. Only DHS and OHA datasets already containing *individual level demographic data of any kind* are required to comply.

Can we use REALD standards to assess eligibility or make referrals for services?

REALD questions are for demographic purposes. The questions shall **not** be linked to eligibility. Answers to REALD questions are optional. People have the right to refuse to answer any question. There is no penalty for those who decline to provide information. We do not recommend use of these categories for referral purposes. However, REALD data **may** be used if the person knows that their demographic information will be used to make referrals, and if they give their **consent**.

Can we rephrase a question to make it easier to read?

If you rephrase or paraphrase questions it can change how people answer. Therefore, the majority of the time, you cannot change questions and categories stated in OARs [943-070-0000 through 943-070-0070](#). **If you want to make a change you must get approval from OHA's Office of Equity & Inclusion (OEI)**. Most questions are derived from validated tools and provide comparability to other datasets, for example, from the American Community Survey (U.S. Census Bureau).

How do we respond to difficult responses from respondents to the REALD questions?

First, it is important to begin with messaging, such as:

*We ask **everyone** about their race, ethnicity, disability, preferred language and interpreter needs. We do so to **ensure that everyone** receives the highest quality of care.*

Second, use common sense. Allow people to respond and use as much of their own description as possible. If a person does not want to answer a question, move on (and code as “decline”). See [here](#) for more detailed guidance to difficult responses such as:

- “Why are you asking me all these questions,” or
- “Can’t you tell by looking at me?”

Racial and ethnic identity

This section describes the three racial and ethnic identity questions in REALD.

Open-ended question:

- How do you identify your race, ethnicity, tribal affiliation, country of origin, or ancestry?
- Question about racial or ethnicity identities with 34 response options
- Question about primary racial or ethnic identity is asked of those who selected multiple categories.

Open-ended question

The first racial and ethnic identity question in REALD is “**How do you identify your race, ethnicity, tribal affiliation, country of origin, or ancestry?**” The intent of this question is to elicit an unprompted response. An open-ended question allows the client, respondent or member to identify the way they choose.

Racial and ethnic identities

We also ask people to select their **racial and ethnic identities from 34 options**. Some options may be unfamiliar, such as the category of “Indigenous Mexican, Central American or South American.” There is an “other” category with space for the respondent to write in their response. There are a few situations that could require using the “other” category. Identities are fluid and personal. We want respondents to feel comfortable. This means providing an option to write in a racial or ethnic identity not listed. Doing so also helps us track emergent populations.

Primary race and ethnic Identity

OARs [943-070-0000 through 943-070-0070](#) states that “**Individuals who select multiple categories shall be asked an additional question regarding their primary racial or ethnic affiliation using the categories listed in section.**” By using response to the **primary racial or ethnic identity question**, you can avoid lumping everyone with more than one racial or ethnic identity as “multi” when you need to report in a way that results in unduplicated counts and percentages. The primary race and ethnic identity question helps us gain a more nuanced understanding of how persons identify based on lived experiences. That said, not everyone has just one primary racial or ethnic identity. Thus, it is important to allow people to indicate **that they do not have just one primary identity** if that is the case. For more about how people with two or more racial or ethnic identities may have more than one primary racial or ethnic identity, see [2015 Pew Research Center](#) report title “Multiracial in America.” In this report, 39 percent of persons who

identified as having two or more races identified themselves as multi-racial (Pew Research Center, 2015).

Race and ethnicity FAQs

Why is there an open-ended question in addition to the race and ethnic categories?

OARs require the use of an open-ended question to elicit an unprompted response.

Having an option to answer an open-ended question is important to people who do not like labels or have other identities outside of categories. The open-ended question provides a way to honor that and helps with data quality, before getting into categories. This question has three key advantages to understand who experience health inequities, as well as to ensure data quality. With this open-ended question, we can:

1. Cross-check the other selections to monitor data quality.
2. Identify new or emerging categories that may be useful to add in the future.
3. Know how a person self-describes their race and ethnicity, which may be useful for research and reporting purposes.

Why not use the OMB federal standards? Why are the race and ethnicity categories combined in REALD?

[OMB](#) minimum standards require two questions about:

1. Hispanic or Latinx ethnicity (yes or no), and

Census study

For many who identify as Latinx or Hispanic, the distinction between race and ethnicity is not clear (Shin, 2015). Some Hispanic respondents would answer the ethnicity question but not the race questions.

The **U.S. Census Bureau's Alternative Questionnaire Experiment (AQE)** found that combining race and ethnicity in a single question reduced missing data and the selection of "some other race":

- When the questions were separated:
 - » 3.5 to 5.7 percent did not respond to the race question
 - » 4.1 to 5.4 percent did not respond to the Hispanic origin question, and
 - » 7 percent selected "some other race."
- When race and ethnicity were combined:
 - » The rate of non-response decreased to one percent, and
 - » Only one percent selected "some other race."
- "Some other race" was the third largest category in the 2010 Census. Of those who selected this option and "no other race" 97 percent were Hispanic (Mathews et al., 2017).

There were concerns that having a single question would decrease the proportion of the population identifying as Hispanic. These concerns were not supported by the [AQE](#) findings or current research being conducted by the U.S. Census Bureau (Shin, 2015).

2. Race in five broad “parent” categories:
 - a. American Indian or Alaska Native (AIAN)
 - b. Asian
 - c. Black or African American
 - d. Native Hawaiian or Other Pacific Islander (NHOPI)
 - e. White.

There are several limitations with these categories:

3. The two-question approach produces some ambiguity for participants who identify as Hispanic or Latinx, and
4. The collapsing of subgroups within the OMB race categories masks significant differences between subgroups (see [Table 2](#)).

In contrast, the REALD standard combines race and ethnic identity into one question. Our goal is to reduce confusion over the difference between race and ethnicity. It is also to improve data quality. The U.S. Census Bureau studied the combined race and ethnicity option. Their results suggest this approach reduces missing data and decreases selection of “some other race.” It also produces higher consistency in race or ethnicity reporting among Hispanics.

Does the OMB allow this? Does REALD roll-up into federal standards?

OMB encourages collection of more granular data, as long as categories can be rolled up into the OMB minimum categories. Further, most federal programs allow a combined question as long as REALD categories can roll-up into OMB categories. See [Table 10](#) for a visual map of how to cross-map REALD and OMB categories.

Why are Cuban or Puerto Rican in the HHS standards, but not REALD?

[HHS](#) standards are based on the OMB standards, that were based on national populations in the United States. In certain areas of the United States the Cuban and Puerto Rican populations are large. However, this is not the case in Oregon. Oregon categories add value in being able to distinguish among Oregon populations. If, for example, you desire another category such as Cuban or Puerto Rican, you can add it. The REALD policy does not forbid more granularity in data collection.

Why do we ask for primary racial or ethnic identity?

When a person reports more than one racial or ethnic identity, it is preferable to use the identity that reflects the person’s primary racial or ethnic identity. This takes away the need for the analyst to rely heavily on the “multi” category in reporting or research. The “multi” option often masks differences within groups as well. That

said, it is also important to recognize and consider those who identify as biracial or multi-racial.

Why the increased granularity in race and ethnicity categories?

Granularity in data standards increases the validity of responses with people being able to better choose any category that reflects their racial and ethnic identities. For example, the option to identify as Vietnamese may be more acceptable than as “Asian” (Laws & Heckscher, 2002). If people do not “see” themselves in the REALD categories, they may say “other.” There is a trade-off between an increase in validity that comes with granularity, and utility, as noted by Aspinall (2009).

Significant differences between subgroups of broader racial and ethnic categories make combining them misleading. The more we understand the nature of inequities, not only between groups (e.g., between individuals of European descent and those of African descent), but within groups (e.g., subgroups within the Hispanic group), the more we can explore and understand causal mechanisms (Commodore-Mensah, Himmelfarb, Agyemang, & Sumner, 2015). See Table 2 for example of inequities between subgroups.

Is “Indigenous Mexican, Central American or South American” a subgroup of American Indian or Alaska Native?

Yes. The American Indian and Alaska Native category includes descendants of people who lived in the Americas before the arrival of the Europeans in 1492. This includes Canada, Mexico, Central America, and South America. The addition of the Indigenous Mexican, Central American or South American category may result in greater accuracy. American Indians and Alaska Natives have traditionally been undercounted in data collection. This may be in part because those who identify as both Native American and Hispanic are often only counted under the Hispanic category when data are reported out.

Differences in historical contexts, lived experiences, and social and health inequities experienced by Indigenous Mexican, Central American or South American may be masked if we do not examine subgroups within those identifying as Hispanic. It is

A limit of the current federal OMB categories (with just six broad racial and ethnic categories) is that it can:

“...mask important inequities in health and health care. More discrete ethnicity groups, based on ancestry, differ in the extent of risk factors, degree of health problems, quality of care received, and outcomes of care. More granular ethnicity data could inform the development and targeting of interventions to ameliorate inequities in health care that contribute to poorer health”

(Ulmer et al., 2009, p. 31).

important to remember that added granularity in data collection provides options later in reporting. There may be times when the focus is on Alaska Natives, for example. The REALD categories makes this possible.

Why does ONE, the Oregon Health Plan (OHP) enrollment and eligibility system, list the Indigenous Mexican, Central American or South American category separately from all the other categories?

People who apply for OHP on ONE first see seven racial and ethnic groups (e.g., White, Black or African American, Hispanic or Latinx). Indigenous Mexican, Central American or South American was added to this list. They then see subgroups under each main group. The hope was this would reduce visual fatigue and make it easier for people to find their racial or ethnic identity. This is one exception to the Indigenous Mexican, Central American or South American category; adding it to the first set of “parent” categories is intended to make it easier for people native to Mexican, Central American or South American areas to find themselves on the application.

What is the intent of the African category? (How would a white South African identify?)

The intent is to collect data about African immigrants that have origins in any black racial group in Africa. Some have asked how white Africans would self-identify. Based on information in the South Africa 2011 Census, a white South African would likely identify as white.

Diversity within

Several studies appear to be contradictory. In one study, Black people born in the Caribbean rated their physical health higher than black people of Caribbean descent born in the United States (Griffith, Johnson, Zhang, Neighbors, & Jackson, 2011). In another study, African-descent Caribbean populations, compared to African Americans born in the United States, were less likely to be screened for breast, prostate, cervical, and colorectal cancer (Consedine, Tuck, Ragin, & Spencer, 2015). A paradox emerged in another study in which male African immigrants, compared to African American males born in the United States, were less likely to be obese and smoke. (They were also more likely to be married and college graduates.) However, African immigrants were also more likely to be hypertensive and have prediabetes or diabetes (O'Connor et al., 2014). These examples illustrate how the more we understand the nature of inequities, the more we can explore and understand causal mechanisms. This is true, not only between groups (e.g., between white persons and Black or African Americans), but also within groups. (Commodore-Mensah et al., 2015).

Why distinguish between people of African descent born in the United States and African immigrants?

African immigrants and African Americans born in the United States have significantly different lived experiences. This includes culture, migration, histories, cultural trauma and language. These experiences may lead to different disease risk factors and lifestyles. Therefore, it is important to collect data for these subgroups separately. If the two subgroups are simply combined, intergroup differences can be masked. This can limit our ability to eliminate social and health inequities. See Table 2 for examples of inequities known among those of African descent born in and outside of the United States. If you want more information about inequities experienced by African immigrant and refugee communities in Multnomah County, check out the Unsettling Profile research study conducted by the Coalition of Communities of Color in 2014 [here](#).

Why distinguish between White subcategories?

Just as we want to identify specific racial and ethnic groups within broader Hispanic, Asian, Black or African American, and other categories, we want to do the same for people who are perceived as or identify as White. The “White” category includes many different subpopulations that have diverse identities, lived experiences and health inequities. As stated by Krieger and colleagues (1999), understanding “heterogeneity among White populations while remaining explicit about shades of White privilege” will help us understand implications related to health and social inequities. Collection of more granular data within groups, including “White” people, helps to identify and track these inequities. For example, lived experiences of Eastern and Western Europeans are greatly influenced by current and past geopolitics. This is in addition to class, race, ethnicity, and other social identities, that result in social and health inequities (Mackenbach et al., 2015; Timonin et al., 2016; Zatonski & Bhala, 2012). Economic and other inequities persist after immigration to the United States. (Akresh, 2011). While not perfect, White subgroups in the REALD standards (e.g., Western European, Eastern European, Slavic, or other White) attempt to distinguish between groups based on similar lived experiences. If you want more information about the extent to which Slavic communities in Multnomah County experience inequities, see a study conducted by the Coalition of Communities of Color in 2014 [here](#). See Table 2 for examples of inequities between subgroups within the White category.

Table 2: Examples of subgroup differences by race and ethnic identities documented in peer-reviewed literature

Group	Selected ¹ subgroups	Author (year), focus of study	Selected ¹ differences between and among subgroups
<p>American Indian and Alaska Native (AIAN)</p>	<p>AIAN in three states:</p> <ul style="list-style-type: none"> • Washington • Oregon • Idaho² 	<p>Gaudino (2008). Infant mortality trend improvements from 1984-87 to 1994-97.</p>	<p>Significant improvements from 1984-87 through 1994-97 in infant mortality rates per 1000 found for AIANs:</p> <ul style="list-style-type: none"> • 14.4 to 4.9 percent (Oregon) and • 17.5 to 6.5 percent (Washington). <p>Similar improvements in Idaho were not detected. Different contexts in state policies and local programs may help explain differences.</p>
<p>Asian</p>	<ul style="list-style-type: none"> • Chinese • Filipino • Vietnamese 	<p>Carliese (2014). Prevalence of chronic cardiovascular, respiratory and pain conditions by subgroups</p>	<p>Prevalence of chronic cardiovascular conditions ranged from:</p> <ul style="list-style-type: none"> • 16.8 percent (Chinese), to • 27.8 percent (Filipino). <p>Prevalence of respiratory conditions ranged from:</p> <ul style="list-style-type: none"> • 34.9 percent (Vietnamese), to • 38 percent (Chinese). <p>Prevalence of pain conditions ranged from:</p> <ul style="list-style-type: none"> • 32.2 percent (Vietnamese), to • 45.3 percent (Filipino).
<ul style="list-style-type: none"> • Asian Indian, • Chinese • Filipina • Other Asian 	<p>Shoemaker & White (2016) Breast and cervical cancer screening</p>	<p>The proportion of women having a Pap smear (pap test) within the last three years ranged from:</p> <ul style="list-style-type: none"> • 66.8 percent (Asian Indian), to • 82.7 percent (Filipina). <p>The following had lower rates than Filipina women:</p> <ul style="list-style-type: none"> • Chinese (68.7 percent), and • Other Asian women (68.1 percent). 	<p>The proportion of women having a Pap smear (pap test) within the last three years ranged from:</p> <ul style="list-style-type: none"> • 66.8 percent (Asian Indian), to • 82.7 percent (Filipina). <p>The following had lower rates than Filipina women:</p> <ul style="list-style-type: none"> • Chinese (68.7 percent), and • Other Asian women (68.1 percent).
<ul style="list-style-type: none"> • Japanese • Korean • Filipino • Vietnamese 	<p>Chu et al. (2012). Rates of having no health insurance in the U.S.</p>	<p>Rates of no health insurance in the United States ranged from:</p> <ul style="list-style-type: none"> • 6.6 percent (Japanese), to • 25.5 percent (Korean). <p>The lowest rates were:</p> <ul style="list-style-type: none"> • Filipino (10.9 percent), and • Vietnamese (19.8 percent). 	<p>Rates of no health insurance in the United States ranged from:</p> <ul style="list-style-type: none"> • 6.6 percent (Japanese), to • 25.5 percent (Korean). <p>The lowest rates were:</p> <ul style="list-style-type: none"> • Filipino (10.9 percent), and • Vietnamese (19.8 percent).
<ul style="list-style-type: none"> • Women in Hawai'i • Chinese • Japanese • Filipina 	<p>Sentell et al. (2014). Maternal outcomes</p>	<p>The percentage of women delivering baby under 2500 grams (about 5½ lbs.) was highest among:</p> <ul style="list-style-type: none"> • Filipina women (11.2 percent) • Japanese women (9.2 percent), and • Chinese women (6.6 percent). 	<p>The percentage of women delivering baby under 2500 grams (about 5½ lbs.) was highest among:</p> <ul style="list-style-type: none"> • Filipina women (11.2 percent) • Japanese women (9.2 percent), and • Chinese women (6.6 percent).

Table 2: Examples of subgroup differences by race and ethnic identities documented in peer-reviewed literature (*continued*)

Group	Selected ¹ subgroups	Author (year), focus of study	Selected ¹ differences between and among subgroups
Pacific Islander	<ul style="list-style-type: none"> • Women in Hawai'i • Native Hawaiian • Other Pacific Islander 	Sentell et al. (2014). Maternal outcomes	<p>Percent of ideal delivery rates was highest among:</p> <ul style="list-style-type: none"> • Native Hawaiian mothers (84.4 percent) <p>Percent of ideal delivery rates was lowest for:</p> <ul style="list-style-type: none"> • Other Pacific Islander mothers (78 percent) <p>Differences between groups by vaginal births after Cesarean was striking:</p> <ul style="list-style-type: none"> • 12.8 percent for Native Hawaiians, and • 25.7 percent for other Pacific Islanders.
Asian and Pacific Islander	<ul style="list-style-type: none"> • Pacific Islander • SE Asian • Indian subcontinent and Asian Indian • Chinese • Japanese • Filipina • Korean 	Parise & Caggiano (2016). Breast cancer mortality by ethnicity and tumor subtype	<p>The proportion of women diagnosed for the first time with invasive breast cancer (primary) at age 45 or younger ranged from:</p> <ul style="list-style-type: none"> • 15 percent (Japanese), to • 30.8 percent (Indian continent or Asian Indian). <p>Percentages of deaths due to breast cancer ranged from 7 percent (Japanese) to 12 percent (Pacific Islander).</p>
Black or African American	<ul style="list-style-type: none"> • People of African descent: • Caribbean born • United States born 	Griffith et al. Relationships among: <ul style="list-style-type: none"> • Ethnicity • Nativity • Depressive symptoms, and • Physical health. 	<p>In examining within group differences by ethnicity:</p> <ul style="list-style-type: none"> • Caribbean people of African descent born in the United States, were more likely to rate their physical health status as fair or poor, compared to African Americans (ref group), [adjusted odd ratio (AOR) = 1.6 (1.07, 2.41)] • People of African descent born in the Caribbean were less likely (AOR = .9, not significant). <p>When examining within group by nativity:</p> <ul style="list-style-type: none"> • People of African descent born in the Caribbean were less likely to rate their physical health as fair or poor, compared to • Caribbean people of African descent born in the United States, [AOR = .5{0.26, 0.87}].
		Consedine et al. Systematic review screenings of these cancers: <ul style="list-style-type: none"> • Breast • Cervical • Colorectal, and • Prostate 	<p>A systemic review of 53 peer review articles revealed that generally people of African descent born in the Caribbean were less likely to be screened, compared to African Americans born in the United States, for cancer of:</p> <ul style="list-style-type: none"> • Breast • Cervical • Colorectal • Prostrate

Table 2: Examples of subgroup differences by race and ethnic identities documented in peer-reviewed literature (*continued*)

Group	Selected ¹ subgroups	Author (year), focus of study	Selected ¹ differences between and among subgroups
	<p>Males of African descent:</p> <ul style="list-style-type: none"> • Immigrants, and • United States born 	<p>O'Connor et al. (2014). Cardiometabolic health</p>	<p>Male African Immigrants were less likely to:</p> <ul style="list-style-type: none"> • Be obese • Smoke <p>They were more likely to be:</p> <ul style="list-style-type: none"> • Married • College graduates <p>Paradoxically, African immigrants were more likely to have:</p> <ul style="list-style-type: none"> • High blood pressure • Prediabetes • Diabetes
<p>Hispanic and Latinx in the United States</p>	<ul style="list-style-type: none"> • Mexican • Mexican American • Central or South American • Other Hispanic 	<p>Borrell & Crawford (2008). Inequities in self-reported hypertension</p>	<p>Percent of Latinx that report diabetes range from:</p> <ul style="list-style-type: none"> • 3.9 percent (Central or South American), to • 9.5 percent (Mexican American). <p>The percentage of Latinx reporting hypertension ranged from:</p> <ul style="list-style-type: none"> • 12.6 percent (Central or South American), to • 18.8 percent (Mexican American).
	<ul style="list-style-type: none"> • Mexican • Central or South American • Other Hispanic, excludes: <ul style="list-style-type: none"> » Puerto Rican » Cuban » Dominican 	<p>Vargus Bustamante et al. (2010). Use of preventive care services among Latinx subgroups</p>	<p>The percentage reporting: poor health ranged from</p> <ul style="list-style-type: none"> • 13 percent (Central or South American) to • 19 percent (Mexican) <p>Diabetes from:</p> <ul style="list-style-type: none"> • 5 to 11 percent (other Latinx) <p>High blood pressure from:</p> <ul style="list-style-type: none"> • 13 to 23 percent (Central or South American) <p>Percent receiving a mammogram ranged from:</p> <ul style="list-style-type: none"> • 60 percent (Mexican), to • 68 percent (Central or South American) <p>Percent receiving a Pap smear (pap test) ranged from:</p> <ul style="list-style-type: none"> • 79 percent (Mexican), to • 85 percent (other Latinx). <p>Percent receiving colorectal cancer screening ranged from</p> <ul style="list-style-type: none"> • 31 percent (Mexican), to • 48 percent (other Latinx).

Table 2: Examples of subgroup differences by race and ethnic identities documented in peer-reviewed literature (*continued*)

Group	Selected ¹ subgroups	Author (year), focus of study	Selected ¹ differences between and among subgroups
	<ul style="list-style-type: none"> • Mexican • Mexican America • Central or South American 	Neighbors, Marquez & Marcus (2008). Leisure-time physical activity inequities	Percent meeting recommendations for physical activity ranged from: <ul style="list-style-type: none"> • 22.7 percent (Mexican), to • 31.9 percent (Mexican America). Percent reporting poor health ranged from: <ul style="list-style-type: none"> • 9.5 percent (Central or South American), to • 14.1 percent (Mexican America). Percent reporting going to college ranged from: <ul style="list-style-type: none"> • 4.3 percent (Mexican), to • 18.3 percent (Central or South American).
White	Immigrant women in Ontario, Canada: <ul style="list-style-type: none"> • Eastern Europe and Central Asia • Western Europe • United States, Australia and New Zealand • Middle Eastern and North African. Northern European	Vahabi et al. (2016). Breast cancer screening inequities among immigrant women by world region of origin.	Screening rates for women age 50-69 ranged: <ul style="list-style-type: none"> • 52.5 percent (Eastern Europe and Central Asia) • 59.5 percent (Middle Eastern and North African) • 62.1 percent (Western European)
	Northern European	Gunderson, Wang & Wang (2011) Global prostate cancer incidence	Prostate cancer incidence appears to correspond to migration and settlement history of Northern Europeans. <ul style="list-style-type: none"> • Northern Europeans have higher rates than Western Europeans • Western Europeans have higher rates than Eastern Europeans.
	Women in the United States: <ul style="list-style-type: none"> • Middle East and North Africa (MENA) • Caucasian 	Salem et al. (2017) In vitro fertilization (IVF) outcome inequities among MENA women in the United States	Significant differences between MENA women and Caucasian women were found with respect to fertilization rates: <ul style="list-style-type: none"> • 73.8 percent (MENA) • 83.7 percent (Caucasian) Miscarriage rate or non-transfer of embryo(s) by IVF: <ul style="list-style-type: none"> • 14 percent MENA • 6 percent Caucasian After controlling for age and BMI: <ul style="list-style-type: none"> • The likelihood of live birth transfer for MENA was less than that of Caucasian women (odds ratio (OR) =0.5 [0.35, 0.85]) • The odds of miscarriage rate and non-transfer were also much higher for MENA (OR=2.6[1.04, 6.27]).

¹ Findings and subgroups highlighted were selected to provide examples of differences between groups. Not all subgroups and not all findings were included. For more information see references.

² Due to very little documentation within group differences among AIAN, this article was selected as it demonstrated some differences by state. This may reflect differing sociopolitical contexts, thus may be of relevance.

Is the Middle East and North Africa (MENA) race and ethnicity category under White or is it separate?

Oregon Administrative Rules place the Middle East and North Africa (MENA) category in the White category, based on OMB. REALD categories mirror [OMB](#) race and ethnicity data standards. However, it is appropriate to have this group stand-alone – not in the white category. This increases data quality, since many people who are Middle Eastern or North African do not see themselves as white (Mathews et al., 2017).

The U.S. Census Bureau conducted extensive research and outreach with the MENA community about a distinct MENA category, rather than a classification under White. The bureau received thousands of public comments in support of testing a separate MENA category. The bureau has actively engaged stakeholders over the past decade to gather feedback on the wording “Middle Eastern or North African” and how to classify the category. Findings from the bureau’s National Content Test (NCT) research shows that “the use of a distinct MENA category elicits higher quality data; and people who identify as MENA use the MENA category when it is available, whereas they have trouble identifying as only MENA when no category is available” (Mathews et al., 2017).

Language and communication

All language questions can be used to measure health inequities in affected populations. Diversity within groups can be as great as diversity between groups. Therefore, it can be helpful to use language questions to create subgroups. For example, together, preferred language and English proficiency can serve as a proxy for acculturation (Fuentes-Afflick, Odouli, Escobar, Stewart, & Hessol, 2014; Lee, O’Neill, Ihara, & Chae, 2013). It can also be a predictor of a person’s ability to access services and programs.

It is important to recognize that responses are context-based (e.g., a person prefers to speak English at doctor visits and wants to communicate with teachers in Spanish, but speaks Zapotec at home). **Specific information about the needs of each person is helpful to avoid assumptions about language access needs.**

The original language questions in the OARs were intended for service-based data systems. These questions can be both functional and demographic in service-based data systems. However, not all OHA datasets are service-based. Some OHA data systems collect data from people whom we do not expect to communicate with in the future, for example students answering the Student Survey. To address this gap, the REALD Implementation Policy specifies required language questions for data systems that are not service-based. Additional details are provided below.

Language questions: Service-based systems

Language questions for service-based systems (see Table 3a) in which there is ongoing communication with clients, members and participants helps:

- Ensure language access by providing:
 - » Written materials in an alternate formats, and
 - » Accommodations, including interpretation
- Aid in system-level planning (e.g., determining the need for interpreters and matching patients to providers who communicate in their preferred language) (Ulmer, Institute of Medicine IOM report, p.5)

Table 3a: Functional language questions for service-based systems

Questions
1. In what language do you want us to speak with you?
2. In what language do you want us to write to you?
3a. Do you need an interpreter for us to communicate with you?
3b. If yes, what kind of interpreter do you need (pick all that apply) *
4. Do you need written materials in an alternate format? If yes, which?
5. How well do you speak English?

Note. All questions are suitable for individuals 5 years or older.*

Response options include:

- Spoken language interpreter (please list)
- American Sign Language
- Deaf Interpreter for DeafBlind and Deaf with additional barriers
- Contact sign language (Pidgen Sign English or PSE)
- Other (please list)

Response from the language questions listed in Table 3a helps to ensure communication access. Responses to these questions can also be used as demographic information. Note the original language questions in the OARs included two separate interpreter questions that likely created confusion for confusion for OHP enrollees* (for more information see [Assessment of Race, Ethnicity, Language and Disability \(REALD\) Data Quality in the Oregon Health Plan ONE System](#)). Therefore, the interpreter questions in Table 3a were reworded to capture the same information as intended by the OARs.

Language questions: non-service-based systems

As noted above, some OHA data systems do not have ongoing communication with participants, such as one-time surveys. Therefore, an alternate set of language questions was developed to be used for demographic purposes only (Table 3b). These questions helps us to:

- Create a profile of languages spoken in communities that can be used to address community level needs.

* For more information from findings of a data quality assessment of OHP and one data see assessment of Race, Ethnicity, Language and Disability (REALD) data quality in the Oregon Health Plan ONE system.

- Identify and address inequities.

Table 3b: Demographic language questions for demographic purposes for non-service-based systems

Questions
1a. Do you speak a language other than English at home?
1b. If yes, what is this language?
If yes to #1a above:
2a. In what language do you prefer to use when speaking with someone outside the home about important matters (such as medical/legal/health information)
2b. In what language do you prefer to use when reading important matters (such as medical/legal/health information)?
3. How well do you speak English?

Note. All questions are suitable for individuals 5 years or older.

REALD language questions FAQs

Can we ask language questions at the beginning to help meet accessibility needs?

Yes. REALD standards do not specify an order to ask REALD questions. Dataset managers can adjust the order of the sections to fit the populations they serve. Further, to ensure that REALD questions are accessible to all, data collectors should ask about the needs of the person before they start the survey. If the person indicates a need for alternate formats or prefers a written or spoken language other than English, a process can be created to ensure full communication and program access.

Can we use all the language questions to capture both demographic information and access needs?

Yes. The original language questions in the OARs (see [Table 3a](#)) were designed for service-based datasets in which there is ongoing communication between the program and the respondent. These questions are meant to facilitate effective communication. But we cannot use the responses from these questions to generalize beyond the context of the program. For example, we cannot assume all people with limited English proficiency who apply for OHP will ask for interpretation. A decision to ask for interpretation may depend on contextual factors such as:

- Geography
- Availability of interpreters in the preferred language, and
- Trust in sharing personal matters with an interpreter who may be a member of the same community as the applicant.

In addition to asking “functional” language questions, you may want to generalize beyond specific context. For example, to explore if a person is less likely to access services in your program who:

- Speaks a language other than English at home, and
- Prefers interpreters or translations for important medical matters.

Then, you should include questions 2a and 2b in Table 3b.

Language and communication FAQs: English language proficiency

Why do we need to ask about English language proficiency? (How well do you speak English?)

Proficiency in English in the United States has a greater bearing on health inequities than preferred written or spoken language (Ulmer et al., 2009). Communication barriers associated with limited English proficiency can adversely affect the quality of care (Ngo-Metzger et al., 2003; Timmins, 2002). It can also result in greater adverse events in hospitals that result in physical harm (Divi, Koss, Schmaltz, & Loeb, 2007). These questions may be a predictor of one’s ability to access services and programs, as well as effects of acculturation on health (Lee et al., 2013).

The English proficiency question can also be used to determine needs for translation and interpretation. A question about preferred written or spoken language alone is not enough. In a study conducted by Shin and Bruno (2003) using 2,000 U.S. Census Bureau data, 55 percent of those who indicated a preference in speaking a language other than English, spoke English very well. In decisions about language needs, actions based on reported preferred written or spoken language need to be specific to those who do not speak and or read English well. Note that the English proficiency question is only suitable for those age 5 and older.

Disability

Why ask about disability?

Health inequities between people with disabilities and people without are well-documented (See for example: Campbell, Sheets, & Strong, 1999; Lennox, Beange, & Edwards, 2000; McGee, 2014; Turk, Scandale, Rosenbaum, & Weber, 2001; Wisdom et al., 2010). Collection of information about a disability allows you to identify and eliminate preventable social and health inequities.

Challenges of defining disability

Altman shows the challenges of defining disability, particularly just one definition of disability. Disability can be any of the following:

- Self-identifying as having a disability
- Defined as having a specific impairment
- Having an impairment with functional limitations
- Focusing on functional limitations specifically, or
- Results of person or environment interaction (environmental barriers and supports).

“ The term “disability” ... has been used to represent almost all of the conceptual components along the disease disability continuum that impacts the person, and it also is used to represent the results of the environmental effects that create a restriction or barrier outside of the person. As such, it has become a word almost without meaning, because it has been used to represent so many different aspects of the process.”

(Altman, 2014, p. 3).

Therefore, there is not just one definition of disability.

How does REALD define disability?

REALD disability questions are designed to capture disability prevalence (population) to identify and address social and health inequities. There was a need to identify people with disabilities who are more likely to experience inequities due to their disability or functional limitation. There was a need to do this well with a minimum set of questions. To ask if and how people identify as people with disabilities does not capture well the population. Many people with disabilities do not identify as disabled (Altman, 2014). To ask people about their medical diagnoses or impairment also has limitations. This is because people can have an impairment, but not have any limitation that puts them at greater risk to experience discrimination or exclusion (Altman, 2014).

For these reasons, the REALD questions were based on functional limitations. Six of the seven disability questions are from the American Community Survey (ACS) survey. The ACS disability questions used today originated from the work of a federal interagency work group brought together in 1997 by the Office of Management and Budget. The work group was told they could have up to six questions (Brault, Stern, & Raglin, 2007). This work group agreed that four domains (vision, hearing, mobility and cognitive functioning) identified most people with disabilities. Two more questions were added “that could be used for

monitoring independent living and the need for services” (Brault et al., 2007). These questions also needed to meet the needs of different agencies collecting disability as a demographic (Brault, Stern, & Raglin, 2007). The resulting six ACS questions must be used as a set to assure a meaningful measure of disability (Brault, Stern, & Raglin, 2007). These functional limitation questions were extensively tested to ensure that they work well to capture most people with disabilities. Notice how none of the questions relating to disability contain the word disability. The intent of these questions is specified in Table 4. See [Appendix A](#) for a summary of what is known about the reliability and validity of the ACS questions.

Table 4: Underlying intent of American Community Survey disability questions

Question	Intent of disability questions
Hearing: Are you deaf or have serious difficulty hearing? (all ages)	To identify people who have: <ul style="list-style-type: none"> » Hearing limitations or difficulty of any kind, even when using a hearing aid (if they wear one). For example, they may have difficulty hearing when they are in a noisy environment, or difficulty distinguishing sounds from various sources.
Vision: Are you blind or have serious difficulty seeing, even when wearing glasses? (all ages)	To identify people who have: <p>Vision problems of any kind, even when wearing glasses or contact lenses (if they wear them). They may have difficulty seeing things close or far away even with glasses.</p>
Memory or cognitive: Because of a physical, mental, or emotional problem, do you have serious difficulty remembering, concentrating, or making decisions? (age 5+)	To identify people, age 5 and older who have some problems remembering or concentrating. They may: <ul style="list-style-type: none"> • Have difficulties finding their way around • Have difficulties concentrating on what they are doing • Forget where they are, or • Forget what month it is. <p>“Making decisions” was added to indicate severity. We do not intend to capture difficulties remembering or concentrating because of common everyday situations such as high workload or stress, or because of substance abuse.</p>
Mobility: Do you have serious difficulty walking or climbing stairs? (age 5+)	To identify people, age 5 and older who have some limitation or problems of any kind getting around on foot. They may: <ul style="list-style-type: none"> • Have difficulty walking more than a block • Not be able walk up or down steps without difficulty.
Self-care: Do you have difficulty bathing or dressing (age 5+)	To identify people, age 5 and older who have difficulty with taking care of themselves without assistance from others. Washing and dressing represent tasks that occur each day. These are basic activities. <p>Note: If the person is using an assistive device or has a person to help them with this care, it is likely they have difficulty with self-care.</p>

Table 4: Underlying intent of American Community Survey disability questions (*continued*)

Question	Intent of disability questions
<p>Independent living: Because of a physical, mental, or emotional problem, do you have difficulty doing errands alone such as visiting a doctor’s office or shopping (age 15+)</p>	<p>To identify people, age 15 and older who have difficulty doing errands alone. The intent of this question about doing errands alone was to “capture underlying difficulties due to mobility and to mind capacity” (U.S. Census Bureau, 2015, pp. C3-43). The question is not intended to capture difficulty in doing errands due to lack of access to transportation or other resources. One should consider the actual errands a person typically does (as opposed to the listed activities of shopping or going to the doctor’s office).</p>

Source: Brault, M., Stern, S., & Raglin, D. (2007). Evaluation report covering disability. American Community Survey Content Test Report; Current Population Survey Interviewing Manual, 2015 (Uses the same ACS questions).

The six ACS disability questions in REALD also have a **follow-up question** if a person answers yes. This follow-up question is, “At what age did this condition began?” The question acknowledges differences in potential social, educational and health inequities by when the disability or limitation first acquired. For example, someone who became hard of hearing before the age of three has a very different lived experience than someone who became hard of hearing later in life. It is important to know about these differences within groups so that we can identify and address inequities. Capturing age data expands the ability of the analyst to:

- Create subgroups by age acquired functional limitation
- Create subgroups by length of time with a functional limitation, and
- Be able to control for length of time with a functional limitation.

These health inequities can be seen in the research that examined the relationship between the age when the disability was first acquired, and health status (Jamoom, Horner-Johnson, Suzuki, Andresen, & Campbell, 2008). Their findings suggested that, those who acquired their disability after age 21, even after controlling for current age and other demographic characteristics, were more likely to report fair or poor health than those who acquired their disability before age 22.

These approaches enable a life course perspective, which

“...recognizes that health trajectories are particularly affected at certain times in life: (1) health status results from the cumulative impact of experiences in the past and the present, (2) the environment affects the capacity to be healthy and function effectively in society, and (3) health inequities reflect inequities that go beyond genetics and personal choice.”

(Krahn et al., 2015, p. 199).

The seventh disability question is from the Behavioral Risk Factor Surveillance System (BRFSS) survey. (Does a physical, mental, or emotional condition limit your activities in any way?). We recommend asking this question *after* the ACS questions as the BRFSS question may be perceived by some people as offensive. This is particularly true from the viewpoint of the social model of disability, in which it is the inaccessible and discriminating society that is disabling, not the individual (Barnes, 2014).

Comparing BRFSS and ACS disability estimates

REALD uses disability questions from both the ACS and BRFSS survey. However, results can differ greatly due to differences in sampling and non-response bias in BRFSS. The percent of people with disabilities in Oregon age 18 and over, ranges from 17.4 (American Community Survey, 2013-2017 estimates) to 26 percent (2016 Behavioral Risk Factor Surveillance Survey) (see [Figure 3](#)). An article by Gettens, Lei & Henry (2015) demonstrated how, by re-weighting Massachusetts BRFSS data, the BRFSS disability prevalence estimates to be more in line with the ACS figures.

Disability over the life-course and why it matters

It is important to distinguish disability as:

- An upstream determinant of health (disablism)
- An outcome, or
- Both.

For example, the age distribution of disability by race and ethnicity shows how after age 60, the number of people with disabilities noticeably increases. In

Self-report vs. perceptions (of others)

A study by Buckley and colleagues (2012) indicated the following did not align:

- Clinical views of impairment in cancer screening, and
- Self-reports by patients.

As noted by the authors, most patients with disabilities who require help with personal care needs, such as bathing or dressing “were not perceived by their clinicians and clinic staff members to have physical limitations that potentially would impede cancer screening” (Buckley et al., 2012, p. 1349). Discordance between perceptions by others and self-report are likely influenced by:

- Visibility of the disability
- Impact of functional limitations, and
- Other contextual factors.

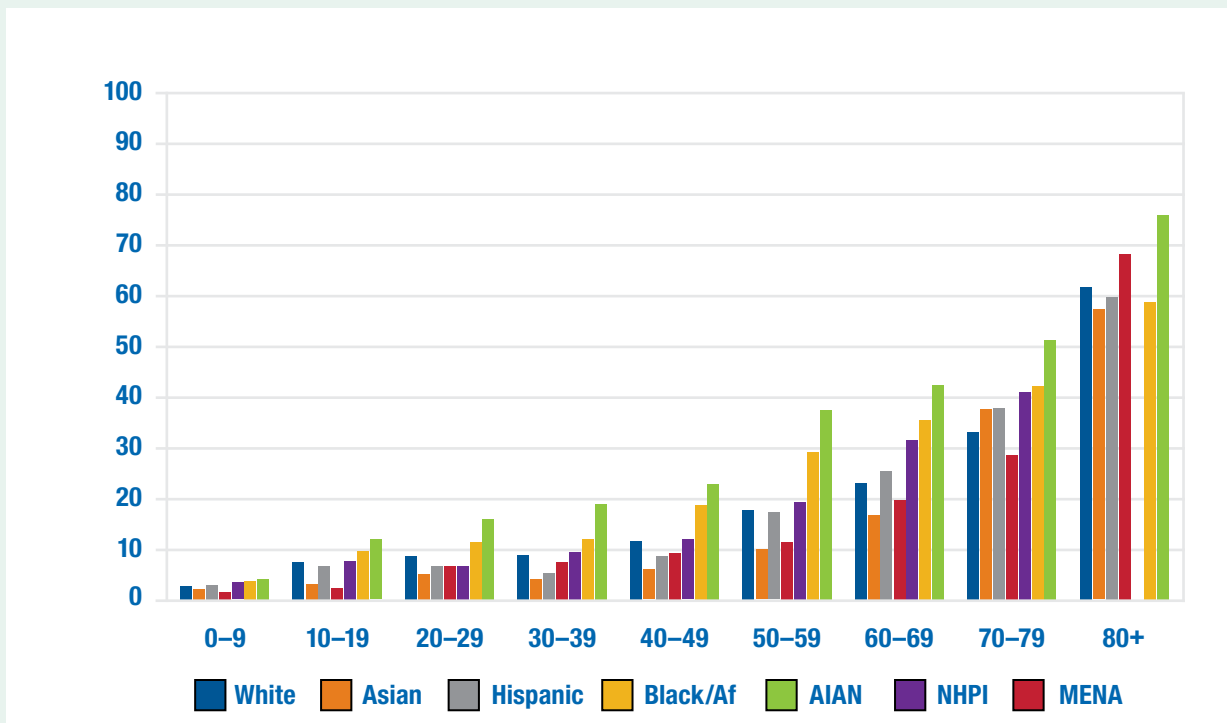
This is even more significant as the study also found that patients with disabilities who require help with personal care needs were less likely to be screened for cervical or breast cancer.

addition, it is not always at the same rate (see Figure 4). It is important to know about these differences within the groups so we can identify and address inequities. To address these differences we can ask when the person acquired the disability or functional limitation. This is in line with the recommendation by Jamoom and colleagues (2008) to allow researchers to “examine possible differences in the relationship between age at onset and self-reported health within specific impairment groups.” For example, analysis of OHP data revealed that about one-third of a sampling of new enrollees reported:

- Having a functional limitation
- Acquiring their disability before age 18, and
- Currently being between age 18 and 44.

This may reflect the impact of disability, as a social determinant of health, leading to enrollment in OHP. (For more information see this report: [Assessment of Race, Ethnicity, Language and Disability \(REALD\) Data Quality in the Oregon Health Plan ONE System](#), page 33).

Figure 4: Age Distribution of Disability by Race or Ethnicity Identity (percentage)



Source: U.S. Census Bureau, American Community Survey (2013-17 5- year PUMS data). AIAN = American Indian & Alaska Native; MENA = Middle Eastern & North African; NHPI = Native Hawaiian & Pacific Islander. Excludes non-civilians. Percents are weighted.

Limitations of the REALD disability questions

OHA designed REALD disability questions to capture disability prevalence (population) to help identify and address social and health inequities. However, there are limits to the use of disability responses. For instance, responses to the REALD disability questions do not indicate severity of the functional limitation, nor can they help ensure that accommodation needs are met (Buckley et al., 2012).

Disability FAQs

Aren't disability questions such as those in the REALD considered protected medical information?

No. These questions focus on “functional limitations” rather than diagnosis, disability identity or impairments. It would be difficult to know the person’s actual medical condition based on answers to these questions.

Can we use these questions to determine eligibility for services?

These questions were designed to capture data about most people with functional limitations. For most social service programs, these questions would not be enough to determine eligibility. Further, you do not want to make eligibility contingent on people answering the REALD questions.

Why not just ask one disability question?

It is not possible to rely only on one question such as “Does a physical, mental, or emotional condition limit your activities in any way?” to identify people with disabilities. This question would not adequately capture all people with disabilities. For example, a person who is deaf and uses American Sign Language (ASL) at Gallaudet University, an inclusive university for deaf and hard of hearing students, may say their hearing loss does not limit their activity. Rather, it would be the non-signers at Gallaudet who would experience “activity limitations.”

Further, if we only asked one question we would not be able to identify and address inequities of different groups of people with disabilities. Not all people with disabilities experience the same inequities. For example, it may be that people who are deaf or have serious difficulty hearing, are less likely to apply for OHP, compared with other people with disabilities. This could prompt us to consider if this is due to communication challenges and limited outreach. As another example, it may be that people who are deaf or have serious difficulty hearing, are less likely to maintain employment, compared to non-disabled people and other people with disabilities. This data could prompt us to consider unique barriers identified by deaf and hard of hearing who work. There may be a separate set of barriers identified by hearing

people using wheelchairs, for example. The seven questions help us consider differences among people with disabilities with respect to social and health inequities.

Can we rephrase the disability questions to make it easier to read?

If you rephrase or paraphrase questions it can change how people answer. This compromises our ability to compare response to other data sources using the same questions used on nearly all federally-sponsored surveys. This includes the U.S. Census Bureau and American Community Survey. We recognize that some people may not know how to answer or interpret the questions. The U.S. Census Bureau developed very helpful [probing tips for interviewers or data collectors](#) to help you ask disability questions.

Why ask about self-care and independent living difficulty?

The intent of the question about bathing and dressing was to capture those who have difficulty with self-care. “Washing and dressing represent tasks that occur on a daily basis and are basic activities.” The intent of the question about doing errands alone was to “capture underlying difficulties due to mobility and to mind capacity” (U.S. Census Bureau, 2015, pp. C3-43).

Why ask about age one acquired a condition or disability?

This follow-up question is to acknowledge that disability status can be both or either an upstream determinant of health or a health outcome. Further, one’s exposure to social and educational inequities (e.g., in educational attainment) is a function of when the person acquired their disability, and how long they have lived with a disability. For example, someone who became hard of hearing before the age of three will have a very different lived experience than someone who became hard of hearing later in life. This is due to differences in language acquisition and language access. This may result in inequities in educational attainment and consequently employment earnings. A study conducted by Loprest and Maag revealed that individuals who acquired a disability before age five, compared with those who acquired a disability later in life, as well as non-disabled people, were less likely to complete high school (2003). It is

The question on independent living and self-care were added by the Office of Management and Budget work group so

“ that [it] could be used for monitoring independent living and the need for services. Ability to take care of oneself, specifically the ability to bath and dress oneself [activities of daily living], and the ability to move around the community without assistance [instrumental activities of daily living] were considered appropriate measures.”

(Brault et al., 2007, p. 4).

important to know about these differences within subgroups so we can identify and address social and health inequities.

What is known about the validity of the demographic disability questions?

Development and testing of the disability questions used in the ACS began in the 1990's. The first use of demographic disability questions was in the U.S. Census Bureau 2000 sample survey. In 2003, the disability questions in the ACS were changed due to a commitment to “clarify the intent of the question” (Stern & Brault, 2005, p. 3). In 2004, members of the ACS working group from the National Center for Health Statistics and U.S. Census Bureau collaborated to conduct an evaluation with in-depth cognitive testing on the ACS disability questions (Miller & DeMaio, 2006). The current demographic disability questions in the ACS are a result of this in-depth testing (Altman, Madans, & Weeks, 2017; Brault et al., 2007). For an in-depth review of the content testing conducted, see [here](#).

3. REALD implementation policy and work plans

[OARs](#) state that “all programs and activities of the Authority (OHA) and Department (DHS) that collect, record or report any demographic data **through any means** shall collect race, ethnicity, preferred spoken, signed and written language, and disability status data in accordance with these rules and implementation policy” ([OAR 943-070-0020](#)). It is important to note that the OARs did not specify or limit the scope of REALD data standards only to data systems over which OHA has direct control. For example, a survey designed and conducted by an OHA program. Many data systems from which OHA “collect, record or report any demographic data through any means,” include data received from external sources. For example, this means hospitals, health providers, funeral homes and so on.

All **new** data systems being developed by OHA that will collect individual level demographic information shall be fully REALD compliant before launch. Key timeline requirements for compliance of **existing** data systems are listed in the REALD Implementation Policy. Timelines are influenced by two things:

1. Whether the data system is prioritized or not, and
2. What degree OHA staff has control over changes needed to bring the system into compliance.

Prioritization of datasets

There are many HB 2134 applicable datasets within OHA. Therefore, it was important to prioritize REALD implementation. Dataset priorities were set based on needs and wants of community stakeholders. Five community meetings took place in Portland, Salem, and Eugene between January and March 2017. Participants questions included:

1. What health issues are important to the communities that you work with and/or you represent, and
2. What are the ways in which you have used any health data or how you want to use that data?

These open-ended questions allowed participants to engage in a robust discussion that enabled them to prioritize:

- Social determinants of health

- Health care and insurance access and utilization issues, and
- Physical health conditions and disease.

Data collected were then analyzed using qualitative grounded theory methods to identify major themes. From those themes, OHA identified fourteen issues as being the most pressing and in need of granular data REALD can provide:

- Chronic disease
- Discrimination
- Education
- Employment
- Food
- Health behaviors
- Housing
- Insurance and enrollments
- Mental health as population
- Physical or built (human made) environment
- Psychosocial and social, mental health conditions
- Service use and screening
- Transportation
- Violence or trauma

This process resulted in the list of prioritized datasets in the REALD Implementation Policy.

Degree of control over data collection

Medium to high control

In some cases OHA staff has control of the data collection process. This includes new questions, revisions, and so on, of several data systems, such as the Student Wellness Survey. In these datasets, the degree of control is high, given enough resources and leadership support within OHA. For this reason, expected compliance is either 18 months or three years depending on whether the dataset is prioritized or not. There is also a work plan required within three or six months (see Table 5)*.

Low control

In data systems dependent on data from external systems, such as hospital settings, OHA staff cannot just “make it happen.” OHA cannot change how the demographic questions are asked, collected and stored. This makes it very difficult to implement the REALD standards. In these cases, even with enough resources and leadership support within OHA, the degree of control is minimal. For this reason, timelines for compliance are not specified.

* Instead of timelines by months, the table contains actual due dates. The “clock” for the timelines began Oct. 1, 2018.

Table 5: Work plan and compliance timelines

Steps	Prioritized dataset or data system?	
	Yes	No
Medium to high control, and data are collected directly by OHA or OHA data vendor	Work plans: Dec. 31, 2018 Compliance: Mar. 31, 2020	Work plans: Mar. 31, 2019 Compliance: Sept. 30, 2021
Low control, and data are collected directly by external partners	Work plans: Sept. 30, 2019 Compliance: Sept. 30, 2021	Work plans: Sept. 30, 2020 Compliance: Sept. 30, 2022
Medium to high control, and data are collected indirectly by external partners	Work plans: Sept. 30, 2019 Compliance: TBD from the work plan assessment process.	Work plans: Sept. 30, 2020

Work plans

It is expected that all new datasets are REALD compliant from the start, and thus will not need a work plan. A work plan shall be completed for each data system not in full REALD compliance, considering:

- Normal agency planning
- Budgeting
- Agency resources, and
- Data collection cycles.

The work plan shall be an **actionable plan with timelines** that detail how the program shall achieve compliance with the REALD standards. Work plan due dates are within the REALD Implementation Policy (see Table 5).

The purpose of the work plan is to track progress REALD implementation and compliance in a data system. OHA provides a work plan template (see [Table 6](#)) to make it easier for staff to complete the work plan.

There are multiple ways to fill out the work plan. It is up to those who must implement REALD to decide how to use the template. There is no right or the wrong answer to questions in the template. Each dataset, beyond REALD, will have different requirements and challenges. Therefore, we highly recommend that you submit a work plan for each individual dataset. In the work plan template are some questions to prompt responses. However, please add information pertinent to the specific dataset. When you complete the work plan consider common issues that could affect implementation of new or revised data collection and management systems to comply with the REALD standards. See below FAQs on this topic.

If the data system is made up of data from various other datasets such as vital records and Medicaid Management Information System (MMIS), please contact the OEI equity & inclusion policy data analyst for guidance.

See [Figure 5](#) for a flowchart which may help to visualize the process and steps required to reach compliance with the REALD standards. The flowchart can help identify risk areas, gaps and challenges that may need to be addressed in the work plan. The [checklist for data collection tools](#) may help to identify and track gaps in data collection tools and the dataset ([Table 8](#)).

Tracking and accountability

All programs that oversee datasets or data systems not yet in full compliance of the REALD data collection standards shall:

- Submit an update of the status of their work plan, and
- Complete an assessment survey disseminated periodically by the OEI equity & inclusion policy data analyst.

Results of the annual survey will be reported to the legislators every two years as required by the OARs. In addition, progress on work plans and compliance of datasets are tracked and reported twice a year to OHA leadership.

Exemptions and extensions

REALD is the law. We are expected to follow it.

If you find that you need to make substantial modifications to the REALD questions or categories, please consult with the OEI Equity & Inclusion policy data analyst for guidance. Also, document the justification for doing so in the work plan:

- Complete a work plan (see [Table 6](#)) with detailed information on exemptions or modifications requested (see [Table 7](#)). and
- Include additional documentation as needed (e.g., cost estimates).

The OHA Director, or a designee, in consultation with the OEI director and the OEI equity & inclusion policy data analyst may grant extensions and exemptions for implementation on a case-by-case basis when:

- A contract requires a program that conducts the work to use defined data collection protocols, tools, algorithms, or databases that specifically forbid changes.
- An external entity provides data used by the program. Also, that external entity has no current obligation by contract, legal mandate or a memorandum of understanding to collect the REALD data elements.
- A researcher has concerns about reporting using the REALD categories because of: statistical unreliability in the data, small sample sizes or privacy.

(See REALD policy for more information on processes).

Before granting an extension the OEI equity & inclusion data analyst will ask the REALD Governance Committee to:

- Advise on exemptions (per 7b in the REALD Implementation Policy), and
- Review extensions granted by the agency (7c; 8c.C).

The REALD Governance Committee will review all exemptions and proposed changes to the standards.

ADA accommodations and language access

The Americans with Disabilities Act of 1990 (ADA) “prohibits discrimination and ensures equal opportunity for persons with disabilities in employment, State and local government services, public accommodations, commercial facilities, and transportation” (ADA 2010). **Data collection tools must be accessible** to all people. Thus, they must be available in alternate formats so they can be accessed by people with a wide range of disabilities. Some examples of alternate formats are:

- Readable Portable Document Formats (PDFs) online
- Extended time for filling out surveys
- Interpreter services

You must provide people who self-report demographic information a notice of alternate formats. Additionally, data collection tools should be accessible to those with limited English proficiency. An example is to provide materials or verbal surveys in other languages. This helps ensure that language is not a barrier to completing the survey. Thus, that people with limited English proficiency are accurately represented in the data. REALD questions are available to use a pre-formatted template, and available in over 20 languages.

Table 6: REALD implementation work plan template

Dataset name	Name of database system or program
About the data system	1. Are data linked to or rely on other data sources? If you answer “yes,” explain.
	2. Are data derived from electronic medical record (EMR) systems?
	3. How are data collected? (e.g., paper, web-based, single source)
	4. Do external parties provide data? If so, name the entities.
	5. From whom, and how are the data received? (e.g., paper, web-based, single source)
REALD elements supported	What REALD questions do you ask in your current data collection? (e.g., have a question about English proficiency) <i>Attach copies of questions within your current data collection tool.</i>
REALD gaps	What are REALD gaps in your current system? (e.g., missing six white subcategories; missing disability questions) <i>See REALD Template as a guide.</i>
Challenges to consider	What are the challenges you face in collection of REALD? (e.g., budget issues; IT; timelines; data collection, entry or maintenance issues; data analysis or reporting issues)
Action for data collection	What actions do you need to take to be REALD data compliant? (e.g., need to make system level changes (state specific changes); system changes OHA needs to make (to receive the data); need to update EMR systems to collect REALD)
Action for reporting	What actions do you need to take to create a report using REALD standards? (e.g., create content; create program tables)
Resources and approval needs	What internal and external resources do you need to bring the data system into compliance? (e.g., an external entity approval process, such as a national association, before changes can be made to how the data are collected; to get training about how to ask REALD questions so that external parties consistently improve data quality)
Memorandum of understanding (MOU), data agreements or contracts	Will there be a need for data agreements or contracts with subcontractors and external partners? Is it possible to build in the contract the requirement that external partners assess and create a plan for REALD compliance?
Team members	OHA:
	Others or external partners:
Timeline	Estimated timeline for major activities and completion:

Cost	Estimated total cost of project for OHA:
	Estimated total cost of project for others or external partners:
	<i>Include complete fiscal statement or quote from vendors.</i>
Request for exemption or extension	Note. Requests for exemptions or extensions should be kept to a minimum. REALD is the law and we are required to follow it.
	Reasons for requesting exemption for:
	1. Data collection:
	2. Reporting using REALD disaggregated categories:
	Reasons for requesting extension for:
	1. Data collection:
	2. Reporting using REALD disaggregated categories:
	If you are requesting an exemption, please also fill out Table 7 and attach it to this work plan when submitting to the OEI Equity & Inclusion data policy analyst.

Please **email your work plan** to Marjorie McGee at marjorie.g.mcgee@dhsosha.state.or.us and **include the following information in the body of your email:**

Your name: _____ Title and position: _____

Role with this dataset: _____ Supervisor's name and position: _____

Are you the primary contact for implementing REALD in this data system? Yes No

If not, please provide name and contact information for that person: _____

Table 7: REALD Modification Checklist

Check each that apply to your request for exemption or modification

✓	Racial or ethnic identity questions
	How do you identify your race, ethnicity, tribal affiliation, country of origin or ancestry?
	Question header: Which of the following describes your racial or ethnic identity? Please check all that apply.
	AIAN categories: American Indian, Alaska Native, Canadian Inuit, Metis, or First Nation Indigenous Mexican, Central American, South American
	Asian categories: Asian Indian; Chinese; Filipino; Hmong; Japanese; Korean; Laotian; Vietnamese; South Asian; Other Asian
	Black or African American categories: African; American African; Caribbean; Other Black
	Hispanic or Latino/a/x categories: Hispanic or Latino/a/x Mexican; Hispanic or Latino/ a/x Central American; Hispanic or Latino/a/x; South American; Other Latino/a/x
	Native Hawaiian and Pacific Islander categories: Native Hawaiian; Guamanian or Chamorro; Micronesian; Samoan; Tongan; Other Pacific Islander
	Middle Eastern or North African categories: Northern African; Middle Eastern
	White categories: Slavic; Eastern European; Western European; Other White
	Don't know
	Don't want to answer
	Other category (Please list) (Note: this includes space to write in the other categories as well as check this option).
	If you selected more than one racial or ethnic identity above, please circle the one that best represents your racial or ethnic identity. (Note: you can use display logics if you are using an online survey, etc. Also for greater clarity, you can also use format suggested in Table 9 in this document.)
	If you have more than one primary racial or ethnic identity please check here: (Note: you can provide options such as "I don't have just one primary identity." See the implementation guide for examples.)

Please fill in specifics about your request for exemption or modification.

State the question as you would modify it.	Why do you want to modify the original question? How does this help?	Is your request to be exempt from asking the entire question? If so, justify why.

Check each that apply to your request for exemption or modification

✓	Racial or ethnic identity questions
	Language questions for client based data systems (Note: you can modify questions to include display logic. You can also combine the question about interpretation and sign language as long as you can gather the type of interpretation the person needs.)
	Do you need written materials in an alternate format (Braille, large print, audio recordings, etc)?
	If yes, which format?
	In what language do you want us to speak with you?
	In what language do you want us to write to you?
	Do you need a sign language interpreter for us to communicate with you?
	If yes, which type do you need us to communicate with you? (ASL, PSE, tactile interpreting, etc.)
	Do you need an interpreter for us to communicate with you?
	How well do you speak English?

	Language questions for non-client or non-member-based data systems
	Do you need written materials in an alternate format (Braille, large print, audio recordings, etc)? (Note: it is good to ask this question even if you do not have the system to produce the format they request. This ensures access to the data collection process for people who need alternate formats.)
	Do you speak a language other than English at home? (Ages 5 and up)

For persons speaking a language other than English (answering yes to the question above):

	What is this language?
	In what language would you prefer to use when speaking with someone outside the home about important matters (such as medical/legal/health information)?
	In what languages would you prefer to read important information (such as medical/legal/health information)?
	How well do you speak English?

	Disability questions
	Are you deaf or have serious difficulty hearing?
	If yes, at what age did this condition begin?

Please fill in specifics about your request for exemption or modification.

State the question as you would modify it.	Why do you want to modify the original question? How does this help?	Is your request to be exempt from asking the entire question? If so, justify why.

Check each that apply to your request for exemption or modification

✓	Racial or ethnic identity questions
	Are you blind or have serious difficulty seeing, even when wearing glasses?
	If yes, at what age did this condition begin?
	Do you have serious difficulty walking or climbing stairs? (Ages 5 and up)
	If yes, at what age did this condition begin?
	Because of a physical, mental, or emotional problem, do you have difficulty remembering, concentrating, or making decisions? (Ages 5 and up)
	If yes, at what age did this condition begin? (Ages 5 and up)
	Because of a physical, mental, or emotional problem, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (Ages 15 and up)
	If yes, at what age did this condition begin? (Ages 15 and up)
	Self-care: Do you have difficulty bathing or dressing?
	If yes, at what age did this condition begin? (Ages 5 and up)
	Does a physical, mental, or emotional condition limit your activities in any way?

	Other requests for modifications, such as when the data are collected, or how the data are collected.

	Effect and actions to mitigate effects of REALD noncompliance
	Please describe any possible negative effect of the modification or exemption from the perspectives of community members most effected.
	Please describe any actions to be taken to mitigate the effects of noncompliance.
	Please describe any possible positive effect of modification or exemption from the perspectives of community members most effected.
	Accessibility
	If the data collection instrument will not be accessible on the basis of disability please explain why.
	If the data collection instrument will not be accessible on the basis of disability please explain how you will mitigate the lack of access.

	Timelines
	If you will not be able to meet timelines for compliance please explain why.

Please fill in specifics about your request for exemption or modification.

State the question as you would modify it.	Why do you want to modify the original question? How does this help?	Is your request to be exempt from asking the entire question? If so, justify why.

Figure 5: Flowchart for REALD implementation in data systems

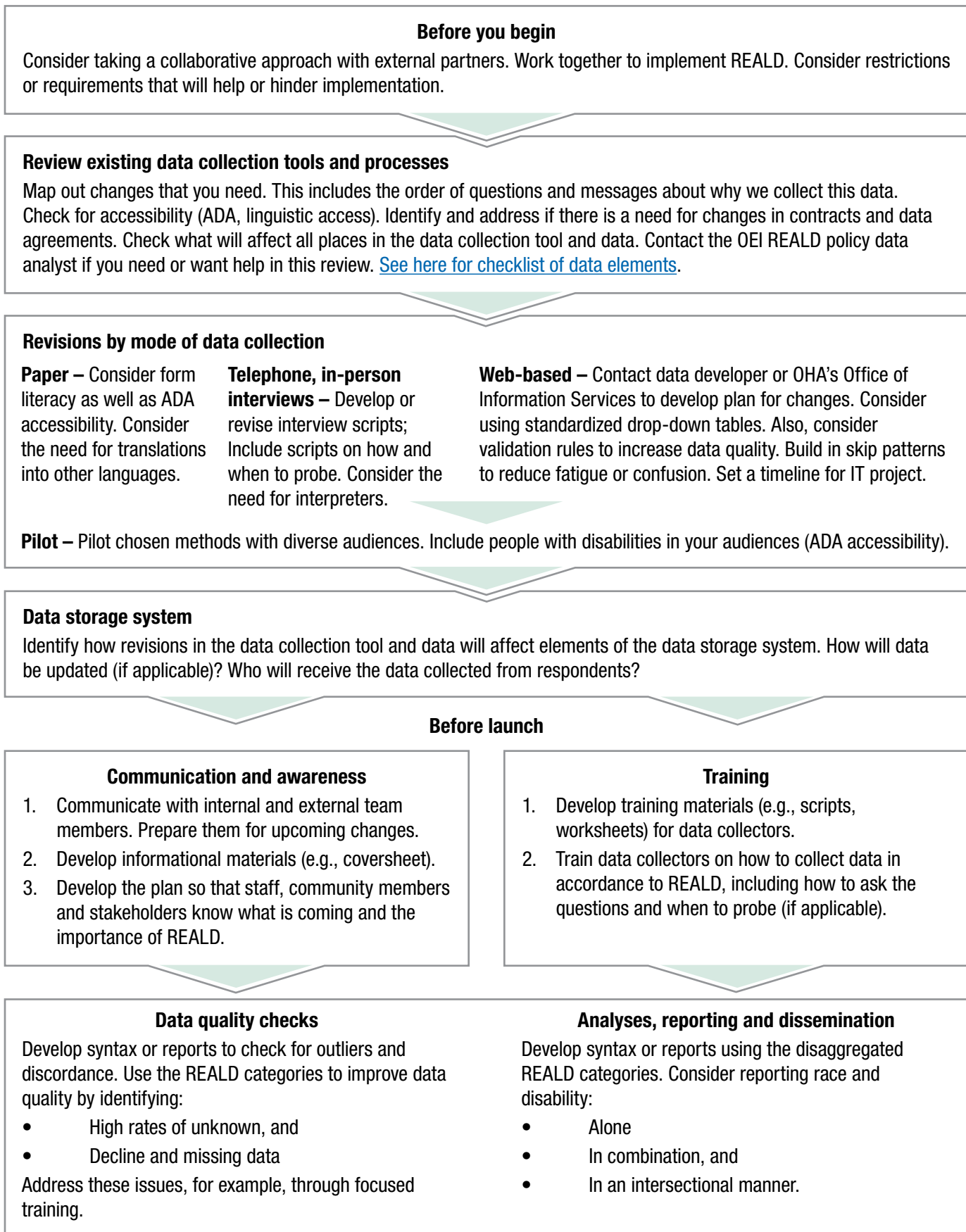


Table 8: Checklist for paper-based data collection tools

✓	REALD category	REALD question or categories	Database (storage of data)	Paper tool for data collection
	Language	Do you need written materials in an alternate format (braille, large print, audio recordings, etc)?	Includes text field for: Do you need written materials in an alternate format (braille, large print, audio recordings, etc.)?	See “REALD question or categories” column.
	Race or Ethnicity	See the “ Messaging: confidentiality, privacy and purpose ” section for sample messaging. Tailor to your program.	n/a	Includes messaging about confidentiality and why the question is being asked.
	Race or Ethnicity	How do you identify your race, ethnicity, tribal affiliation, country of origin, or ancestry?	Includes text field for: How do you identify your race, ethnicity, tribal affiliation, country of origin, or ancestry?	Includes open-ended question (see “REALD question or categories” column)
	Race or Ethnicity	Which of the following describes your racial or ethnic identity? Please check all that apply.	n/a	Includes question on paper tool (see “REALD question or categories” column).
	Race or ethnicity	n/a	n/a	Includes header: American Indian and Alaska Native
		<ol style="list-style-type: none"> 1. American Indian 2. Alaska Native 3. Canadian – Inuit, Métis and First Nation 4. Indigenous Mexican, Central American and South American 	Includes four fields for the American Indian and Alaska Native category	Includes checkbox or radio button or a “yes” and “no” for each race or ethnicity subcategory (see “REALD question or categories” column)
	Race or ethnicity	n/a	n/a	Includes header: Asian
		<ol style="list-style-type: none"> 1. Asian Indian 2. Chinese 3. Filipino 4. Hmong 5. Japanese 6. Korean 7. Laotian 8. Vietnamese 9. South Asian 10. Other Asian 	Includes 10 fields for the Asian category	Includes checkbox or radio button a “yes” and “no” for each race or ethnicity subcategory (see “REALD question or categories” column)
	Race or ethnicity	n/a	n/a	Includes header: African American or Black and
		<ol style="list-style-type: none"> 1. African (Black) 2. American African 3. Caribbean (Black) 4. Other Black 	Includes four fields for the African American or Black category	Includes checkbox or radio button or a “yes” and “no” for each race or ethnicity subcategory (see “REALD question or categories” column)

✓	REALD category	REALD question or categories	Database (storage of data)	Paper tool for data collection
	Race or ethnicity	n/a	n/a	Includes header: Hispanic and Latinx and
		<ol style="list-style-type: none"> 1. Mexican 2. Central American 3. South American 4. Other or Latinx 	Includes four fields for the Hispanic, Latinx category	Includes checkbox or radio button a “yes” and “no” for each race or ethnicity subcategory (see “REALD question or categories” column)
	Race or ethnicity	n/a	n/a	Includes header: Native Hawaiian and Pacific Islander and
		<ol style="list-style-type: none"> 1. Native Hawaiian 2. Guamanian or Chamorro (highly recommend breaking these into two separate fields) 3. Marshallese, Micronesian, Palauan 4. Samoan 5. Tongan 6. Other Pacific Islander 	Includes six fields for the Native Hawaiian and Pacific Islander category. (Optional but highly recommended – use seven fields and separate Guamanian from Chamorro.)	Includes checkbox or radio button or a “yes” and “no” for each race or ethnicity subcategory (see “REALD question or categories” column)
	Race or ethnicity	n/a	n/a	Includes header: Middle Eastern and North African and
		<ol style="list-style-type: none"> 1. Middle Eastern 2. North African 	Includes two fields for the Middle Eastern and North African category	Includes checkbox or radio button or a “yes” and “no” for each race or ethnicity subcategory (see “REALD question or categories” column)
	Race or ethnicity	n/a	n/a	Includes header: White and
		<ol style="list-style-type: none"> 1. Slavic 2. Eastern European 3. Western European 4. Other White 	Includes four fields for the White category	Includes checkbox or radio button or a “yes” and “no” for each race or ethnicity subcategory (see “REALD question or categories” column)
	Race or ethnicity	n/a	n/a	Includes header: Other Categories and
		<ol style="list-style-type: none"> 1. Other 2. Text box or space for #1 above 3. Don’t know 4. Don’t want to answer 	Includes four fields for three optional categories (“Other” requires two fields)	Includes checkbox or radio button a “yes” and “no” for each race or ethnicity subcategory (see “REALD question or categories” column) and
		If you selected more than one racial or ethnic identity above, please circle the one that best represents your racial or ethnic identity.	Includes field for primary racial or ethnic identity	Includes instruction to indicate primary race or ethnic identity

✓	REALD category	REALD question or categories	Database (storage of data)	Paper tool for data collection
		Includes option for someone to state they have more than one primary racial or ethnic identity.	Includes checkbox, radio button or a “yes” and “no”	If you have more than one primary racial or ethnic identity, please check here:
	Language	Do you need written materials in an alternate format (braille, large print, audio recordings, etc.)?	Includes a response field for the alternate format question	Includes checkbox or radio button or a “yes” and “no”, or for these response options: <ul style="list-style-type: none"> • Yes • No • Don’t known • Don’t want to answer and
		If yes, which format?	Includes text field for: If yes, which format?	Includes follow-up open-ended question: If yes, which format?
	Language	In what language do you want us to speak with you?	Includes text field for: (see “REALD question or categories” column)	Includes open ended question (see “REALD question or categories” column)
	Language	In what language do you want us to write to you?	Includes text field: (see “REALD question or categories” column)	Includes open ended question (see “REALD question or categories” column)
	Language	Do you need a sign language interpreter for us to communicate with you?	Includes field for response to sign language interpreter question	Includes checkbox or radio button to indicate one of these response options: <ul style="list-style-type: none"> • Yes • No • Don’t know • Don’t want to answer
	Language	If yes, which type do you need us to communicate with you? (American Sign Language (ASL), Pidgen Signed English (PSE), tactile interpreting, etc.)	Includes text field for: If yes, which type do you need us to communicate with you?	Includes follow-up open ended question: If yes, which type do you need us to communicate with you? (see “REALD question or categories” column)
	Language	Do you need an interpreter for us to communicate with you?	Includes field for response to question	Includes checkbox or radio button to indicate one of these responses: <ul style="list-style-type: none"> • Yes • No • Don’t know • Don’t want to answer

✓	REALD category	REALD question or categories	Database (storage of data)	Paper tool for data collection
	Language	n/a	Includes field for response to question	Includes checkbox or radio button or a “yes” and “no” for these response options: <ul style="list-style-type: none"> • Very well • Well • Not well • Not at all • Don’t know • Don’t want to answer
	Disability	See implementation guide and template for sample messaging	Include messaging	Includes messaging about confidentiality and why you are asking the question
	Disability	Are you deaf or have serious difficulty hearing?	Includes field for hearing disability such as DEAR*	Includes checkbox or radio button to indicate one of these responses: <ul style="list-style-type: none"> • Yes • No • Don’t know • Don’t want to answer (add note about age limits, if applicable, see “REALD question or categories” column)
		If yes, at what age did this condition begin?	Includes field for age such as DEAR* age	Includes space for respondent to write in age
	Disability	Are you blind or have serious difficulty seeing, even when wearing glasses?	Includes field for vision disability such as: DEYE*	Includes checkbox or radio button to indicate one of these responses: <ul style="list-style-type: none"> • Yes • No • Don’t know • Don’t want to answer (add note about age limits, if applicable, see “REALD question or categories” column)
		If yes, at what age did this condition begin?	Includes field for age such as DEYE* age	Includes space for respondent to write in age

✓	REALD category	REALD question or categories	Database (storage of data)	Paper tool for data collection
	Disability	Do you have serious difficulty walking or climbing stairs? (Age 5 and up)	Includes field for mobility disability such as DPHY*	Includes checkbox or radio button to indicate one of these responses: <ul style="list-style-type: none"> • Yes • No • Don't know • Don't want to answer (add note about age limits if applicable – see “REALD question or categories” column)
		If yes, at what age did this condition begin?	Includes field for age such as DPHY* age	Includes space for respondent to write in age
	Disability	Because of a physical, mental, or emotional problem, do you have difficulty remembering, concentrating, or making decisions? (Age 5 and up)	Includes field for cognitive disability such as DREM*	Includes checkbox or radio button to indicate one of these responses: <ul style="list-style-type: none"> • Yes • No • Don't know • Don't want to answer (add note about age limits if applicable – see “REALD question or categories” column)
		If yes, at what age did this condition begin? (Age 5 and up)	Includes field for age such as DREM* age	Includes space for respondent to write in age
	Disability	Because of a physical, mental, or emotional problem, do you have difficulty doing errands alone such as visiting a doctor's office or shopping (Age 15 and up)	Includes field for independent living disability such as DOUT*	Includes checkbox or radio button to indicate one of these responses: <ul style="list-style-type: none"> • Yes • No • Don't know • Don't want to answer (add note about age limits if applicable – see “REALD question or categories” column)
		If yes, at what age did this condition begin? (Age 15 and up)	Includes field for age such as DOUT* age	Includes space for respondent to write in age

✓	REALD category	REALD question or categories	Database (storage of data)	Paper tool for data collection
	Disability	Self-care: Do you have difficulty bathing or dressing	Includes field for self-care disability such as DDRS*	Includes checkbox or radio button to indicate one of these responses: <ul style="list-style-type: none"> • Yes • No • Don't know • Don't want to answer (add note about age limits if applicable – see “REALD question or categories” column)
	Disability	If yes, at what age did this condition begin? (Age 5 and up)	Includes field for age such as DDRS* age	Includes space for respondent to write in age
		Does a physical, mental, or emotional condition limit your activities in any way?	Includes field for self-care disability such as DLIM*	Includes checkbox or radio button to indicate one of these responses: <ul style="list-style-type: none"> • Yes • No • Don't know • Don't want to answer (add note about age limits if applicable – see “REALD question or categories” column)

* The following in the database column regarding disabilities reflect ACS field names:

- DEAR – Deaf or having serious difficulty hearing
- DEYE – Blind or having serious difficulty seeing, even when wearing glasses
- DPHY – Serious difficulty walking or climbing stairs
- DREM – Serious difficulty remembering, concentrating, or making decisions
- DDRS – Difficulty bathing or dressing
- DOUT – Difficulty doing errands alone

DLIM refers to the activity limitation question: Does a physical, mental, or emotional condition limit your activities in any way?

It helps to be consistent in name use, especially if you use other datasets that contain some of the same data elements. That said, how you name the field in the database is up to each program and their own policies or preferences.

Work plan frequently asked questions

What data collection, data entry and database maintenance issues should we consider to complete the work plan?

Please consider the following questions:

- How will the new standards affect data entry?
- How many more pages will there be in the data collection tool?
- What is the increased size or cost of the database?
- Will it affect the ability to query your database?
- How will you combine old data with new data in a single database?
- Are there inherent limits on your data collection tool besides cost?
- What are the time and resources needed to create new data dictionaries and other data documentation
- How much time and money is needed to test the new data collection tool?

What analysis or reporting issues should we consider to complete the work plan? Please consider the following questions:

- How will you do trend analysis?
- Can new categories be rolled-up to existing categories?
- How will changing the system mid-year affect analysis and reporting?
- Will data matching algorithms be affected? If so, how?

Note: Please consult with the OEI equity & inclusion policy data analyst for tools developed to aggregate REALD categories to intermediate categories and/or to the OMB standards when required to do so.

Frequently ask questions – data exemptions and extensions

Does the REALD Data Governance Advisory Committee have criteria they use to decide exemptions or modifications?

Yes. The committee developed a list of guiding principles. At the heart of the principles is an assumption that exemptions and modifications reflect equity issues. OHA staff need to demonstrate how requested exemptions or modifications would not affect equity. The burden of proof is on OHA staff responsible for the data system. Please consult the OEI equity & inclusion policy data analyst if you want more information.

REALD equivalent population estimates aren't available to compare our findings. Is this a reason for an exemption?

No. There are ways to estimate granular racial and ethnic denominators using American Community Survey and other data sources. [See here for more information.](#)

The survey, with sensitive questions (e.g., sexual behaviors), was designed so people could answer questions directly to improve response rates and validity. However, if we make this survey accessible with sign or language interpreters or provide help to individuals who complete the survey it would bias the response. Is this a reason for an exemption or extension?

No. Using disability or other characteristics as basis for exclusion on surveys does not lead to equity in our efforts to identify and address inequities. Please consult with the OEI equity & inclusion policy data analyst for technical help.

We can pull REALD information from other datasets into our dataset. Is this a reason for an exemption?

Perhaps. The issue will be about the accuracy, completeness and date of demographic data in your dataset. Please consult the OEI equity & inclusion policy data analyst if you want more information about this issue.

We often link to other datasets not in compliance to calculate and report on certain indicators (e.g., birth and abortion data used together to calculate pregnancy). Is this a reason for an exemption?

No. REALD is the law. We are expected to follow it. We know that compliance with REALD standards will be difficult when datasets rely on data from external partners and there is low degree of control by OHA on data collection. However, collaborating with your partners to explore what it would take to comply and documenting this in the work plan will help us determine future next steps for OHA.

The cost of implementing REALD is too steep. Is this enough of a reason for an exemption or extension?

REALD is the law. We are expected to follow it. Please use the work plan process to document what it will take to be following the REALD standards. Programs should present the most complete plan achievable for REALD implementation in the work plan. Staggered rollout, budget needs, limitations in control of data collection devices or data transfer layouts are relevant to the plan. However, these issues do not remove the need to present the most complete plan achievable and identify changes to completely implement REALD. Finally, the costs may justify an extension due to



additional steps required (outlined in the work plan) to obtain funding, but likely not an exemption.

The validity of some of the REALD questions (and the large number of granular categories) is unknown. Is this a reason for an exemption or extension?

No. Please consult with the OEI equity & inclusion policy data analyst for technical help. There are some possible procedural solutions to help address these concerns.

The readability of some REALD questions exceed the 6th or 7th grade level. Can we modify the questions?

No. REALD is the law. We are expected to follow it. Please consult with OEI's equity & inclusion policy data analyst if you are working with a specific group of people for whom reading comprehension and literacy is particularly challenging.

4. Data collection

What to collect

A strong data collection process is integral in obtaining high quality data. This chapter discusses some key points and concepts about REALD data collection, guidelines for designing and formatting the questions, and the different ways REALD data can be collected, mapped, and stored.

REALD is the law and we are expected to follow it. At the same time, know that there is not a “one-size-fits-all” solution for REALD implementation. We want consistency in the wording of the questions and categories, but how data collection is done depends on contextual factors. It is important to consider **how** the data collection is done, and with **whom**; if the data collection is done online, you can use the template as the guide, but the order and presentation of the REALD questions may change.

Further, you will also need to consider **how** you will use the language data collected – is it primarily to track and improve language access, or is it used as demographic information? You will get different data depending on the type of language questions asked (as on the survey template, or the alternate set of language questions in the REALD policy). For example, someone may indicate a preference for us to speak with them in English, but their primary language is not English. Further, they may not want an interpreter for several reasons (e.g., speak fluently in English, don’t trust that we will get a good interpreter, not clear that interpreters are available, fear of interpreter knowing too much about their personal life). Thus, you may want to use both sets of language questions if you wanted to capture both language access (functional) and language as a demographic statistic.

Those completing the REALD questions should **self-report** their own responses; data collectors should not make assumptions. The OARS specifies that “Authority, Department, or Contractor shall not assume or judge ethnic and racial identity, preferred signed, written and spoken language, or disability without asking the individual” (OAR [943-070-0020](#) (3)(a)).

The nature of disparity research is that it is not easy to collect the data. Often the group experiencing inequities is relatively small and does not have as much visibility. For this reason, REALD categories and questions shall not be omitted in the data collection process even if the expected size of people in a subgroup is thought to be so small that it will be difficult to report the disaggregated data. As stated in the Implementation Policy, the data standards represent **minimum standards**,

and are not intended to limit the collection of needed data. Oregon Administrative Rules ([943-070-0000 thru 943-070-0070](#)) **requires all** the REALD questions and categories to be included in data collection containing demographic data of any kind. However, there may be cases in which it does not make sense to ask some of the questions, such as the need for a sign language interpreter during a telephone-based survey.* (But you should ensure that the survey is accessible).

Language questions

You will need to consider **how** you might want to use the language data collected:

- Is it mainly to track and improve language access, or
- Is it used as a demographic?
- Or both?

There may be cases where it does not make sense to ask all the language questions exactly as stated in the OARs. Therefore, an alternate set of language questions for none-service-based systems (see the list of questions is in the REALD Implementation Policy). These questions stay true to the scope and intent of HB 2134.

You will get different data depending on the language questions you ask (as on the survey template or the alternate set in the REALD policy). For example, someone may indicate a preference for us to speak with them in English. However, their primary language may not be English. Further, they may not want an interpreter for reasons related to access or quality.

You may want to use both sets of language questions if you want to capture both language access (functional) and language as a demographic.

REALD data collection templates and checklists

REALD questions are available in a pre-formatted template. In order to accommodate different settings (e.g., collection for service-based data systems, by parents for a child), there are different types of templates for use by OHA programs. For more information see here (standalone document about the various paper-based templates). Templates are available in 20 different language translations. However, you do not have to use these templates.

If your data collection tool is not paper-based or you are unable to use the template format, you can still use them to:

* For people who are deaf, hard of hearing, or have communication difficulties, the Video Relay Service (VRS) provides accessible telecommunication services via sign language interpretation in English or Spanish, and real-time captioning (see glossary for more information).

- Provide an at-a-glance view of all the REALD data categories and questions.
- Reformat to fit the data collection tool you use (work with Publications and Creative Services to access the translated text).
- Maintain fidelity of interpreted or translated questions using the REALD data collection template.

See here for a [Checklist of REALD items required for a paper-based survey](#).

Primary racial or ethnic identity question

The primary racial or ethnic identity question avoids use of “multi” to report race and ethnicity. However, it may be that someone has more than **one primary** racial or ethnic identity. So, we suggested adding another choice such as, “I have **more than one primary** racial or ethnic identity.” Stating this response option in the positive may help individuals think about the question more before answering. At the same time, it is helpful to know if the person identifies as biracial or multiracial. This could be a salient predictor of certain social health outcomes. Therefore, give plenty of choices so the data for primary racial and ethnic identity can be used to identify and address inequities. See [Table 9](#) for an example of how this could be displayed in a paper-based data collection form or tool.

Table 9: Primary racial or ethnic identity (example text)

If you checked more than one category above, is there one you think of as your primary racial or ethnic identity?

- Yes. Please circle the one you think of as your primary racial or ethnic identity.
- No. I have more than one primary racial or ethnic identity
- No. I identify as Biracial or Multiracial.
- N/A. I only checked one category above.
- Don't know.
- Don't want to say.

Clarification for select racial or ethnic identities

Some REALD racial and ethnic categories may be new or confusing to some people. Therefore, you may want to add clarifying text in parentheses for some categories. While ancestry or country of origin do not necessarily equal identities, there is a list below of countries and associated categories.

- **Asian Indian:** This term was added by the U.S. Census Bureau to avoid confusion with American Indian. Includes those who identify as from India.
- **South Asia:** Bangladesh, Bhutan, Maldives, Myanmar (Burma), Nepal, Pakistan, and Sri Lanka. Afghanistan is also considered South Asian by some.
- **Micronesian, Palauan or Marshallese:** This category was intended to include those affected by the Compact of Free Association (COFA). This includes the Federated States of Micronesia (Yap, Chuuk, Pohnpei and Kosrae), Palau and the Marshall Islands.
- **Middle Eastern:** These countries commonly include: Bahrain, Cyprus, Iran, Iraq, Israel, Jordan, Kuwait, Lebanon, Oman, Palestine, Qatar, Saudi Arabia, Syria, Turkey, United Arab Emirates and Yemen. Afghanistan and Azerbaijan is also considered in the Middle East by some.
- **North African:** The U.S. Census defines North Africa as Algeria, Libya, Egypt, Morocco and Tunisia.
- **Eastern Europe:** Countries considered in Eastern Europe (excluding Slavic) includes: Armenia, Azerbaijan, after Albania, Estonia, Georgia, Hungary, Latvia, Lithuania, Moldova, and Romania. Afghanistan is also considered part of Eastern Europe by some.
- **Slavic:** Bosnia and Herzegovina, Bulgaria, Belarus, Czech Republic, Croatia, Macedonia, Montenegro, Poland, Russia, Serbia, Slovakia, Slovenia and Ukraine.
- **Western Europe:** Andorra, Austria, Belgium, Denmark, England, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Liechtenstein, Luxembourg, Malta, Monaco, Netherlands, Norway, Portugal, San Marina, Spain, Sweden, Switzerland and the United Kingdom.

The purpose of the list above is to provide guidance for those who may be unclear about some REALD racial and ethnic categories. Keep in mind that these categories:

- Are socially constructed
- Are often structured by geopolitical history and events
- May not reflect how an individual from any of these countries identifies, and

- Are not always well defined. There are many different definitions, particularly with regard to the “Middle East.” These may overlap with what is considered “South Asia” or, in some cases, Eastern Europe.

It is **essential to let people self-identify** their racial or ethnic identity in the way they chose.

Staff training

To collect accurate data, it is imperative to train staff involved in data collection processes. The language and attitude that data collection staff use to asks questions and how they respond to a participant’s comments can have significant influence on data quality. Therefore, to ensure high quality and reliable data, it is essential to train data collection staff on how to ask the questions in a trauma-informed manner.. Crucial training elements include:

- REALD data collection standards
- How to explain what REALD is and why we ask, and
- How to ask questions in a culturally appropriate manner
 - » Taking a trauma-informed approach, and
 - » Addressing questions, concerns and “challenges.”

REALD training options:

- You can use the training developed by OHA, OEI specific for REALD data collection
- Work with OEI’s equity & inclusion policy data analyst, or
- Work with OEI’s training coordinator to customize a REALD training for your program.

Response matrix

Barriers in demographic data collection are:

- Concern of negative reactions from people
- Profiling, or
- Asking people about their race or ethnicity (Hasnain-Wynia & Baker, 2006), language preferences or disability.

To address these concerns see here for an [extensive response matrix](#). This provides detailed guidance of how to respond to difficult questions from respondents such as “Why are you asking me all these questions” or “Can’t you tell by looking at me?”

Disability questions – when to probe

You cannot rephrase the disability questions. Changes in wording it may cause a question to not align with those in federal surveys, such as the Census. Please consult with the OEI Equity & Inclusion policy data analyst if you have concerns about question readability. However, there are some [probing suggestions specific to disability](#) (see page 24 in this link) developed by the U.S. Census Bureau. For example:

- **Application assister:** “Because of a physical, mental or emotional condition does your son have serious difficulty concentrating, remembering, or making decisions?”
- **OHP applicant or member:** “Well, my son has ADD.”
- **Application assister:** “Does that cause him to have serious difficulty concentrating, remembering, or making decisions?”

Design of data collection tools

Language and ADA Accessibility

Data collection tools should be accessible to those with **limited English proficiency**. This helps ensure that language is not a barrier to complete the survey. Also, that people with limited English proficiency are more accurately represented in data. REALD questions are available in a pre-formatted template and in over 20 languages. OHA staff can work with the publications office to customize – you can start by using one of the pre-formatted template.

Data collection tools must be **ADA accessible** to all people. This means tools must be available in alternate formats so they can be accessed by people with a wide range of disabilities. Examples are readable PDFs online, extended time for filling out surveys, interpreter services, etc. The Americans with Disabilities Act of 1990 (updated in 2016) prohibits exclusion of persons with disabilities, indirectly or directly, from data collection because of their disability. Further, OHA policy requires that we foster an inclusive environment where different communications needs are identified and met.

Accessibility and alternate formats in surveys and electronic formats

People who self-report demographic information must receive the notice of alternate formats on our data collection tool and other materials they receive from us. Sometimes our surveys and other web-based programs are not accessible, or minimally so, to people who are legally blind or have low vision. We recommend you ask about the need for written materials in an alternate format (if applicable to

the program). If the response says “yes” then a second question would appear. The question asks if the person needs the survey or web-based program in an alternate format. If the person said yes to the second question, they can be redirected to another (survey). That survey then collects more information about the alternate format they need and their contact information.

OHA is required to inform persons of the availability of alternate services, forms, formats and activities. There is no exception. OHA has an affirmative obligation to let the public know that if they need an accommodation to participate in an OHA activity they have the right to ask for it. Once each request is received it is reviewed and a determination is made about the accommodation. Current OARs [943-005-0010](#) require this as does [OHA’s Alternate Formats and Language Access Services Policy](#).

When creating documents that have an impact on the public, it is critical that we consider accessibility at the drafting stage. Accessibility guidelines are a great tool. [State Agencies’ Website Guidelines for Usability and Accessibilities](#) is one of such tool. It should be reviewed throughout the drafting process. This is a great resource not only for web-based documents, but any document.

Accessibility: an ethical imperative

As McDonald and Raymaker note, research practice “is not always conducive to accommodating needs and rarely considers making disability accommodations an ethical imperative” (2013, p. 2169). To exclude people from data collection because of disability or language access needs affects the full participation of people with disabilities and people with limited English proficiency in many ways. It sends a message that we do not value them enough to figure out how to make the research process fully accessible. In addition, such exclusion limits our knowledge and ability to identify and address health and social inequities.

As aptly stated by Meyers and Andresen (2000),

“... it much easier to use arguments of expediency or distorted canons of rigor to ignore or to exclude persons with disabilities ... By so doing, we have systematically excluded from our research, and, therefore, from our health planning, healthy policy, and health evaluation activities, the voices and ideas, for not all of those excluded have voices. . . As a consequence, we may have deceived ourselves about the effectiveness and efficiency of health services.”

(2000, p. S5).

It is important to reframe the issue of accommodations. This is both an ethical and legal issue. It can not be thought of as a burden on the state or researchers, or a problem that interferes with validity and reliability. Whether it be based on disability or language, it needs to be an ethical challenge we address. In doing so, we benefit from an increase in data quality. This quality data guides our efforts to identify and address inequities. Fortunately, many authors offer suggestions we can use to address these challenges. See the reference section for information on their articles (Barnett, Klein, et al., 2011; Barnett et al., 2017; Barnett, McKee, Smith, & Pearson, 2011; McDonald & Raymaker, 2013; McKee et al., 2015; McKee et al., 2012; Meyers & Andresen, 2000; Oswald et al., 2014).

Messaging: confidentiality, privacy and purpose

REALD data may be sensitive for people to provide. It is personal information, it is important to explain:

- Why their demographic information is collected, and
- How this information is protected.

Below are three examples of scripts for collecting race or ethnicity, disability and language data.

- We want to guarantee that everyone receives the highest quality of care. We also want to

Messaging in general

Baker and colleagues conducted several studies to test different types of messaging asking patients about their racial and ethnic identity (Baker et al., 2005; 2007). In the latest study in 2007, the authors tested five messaging statements with 563 Californians (18.7 percent were white; most were people of color). The intention of the messaging statements was to increase the comfort level of respondents answering questions about their race and ethnic identity (Baker et al., 2007, pp. 1041-1042):

1. Quality monitoring

“We want to make sure that all our patients get the best care possible. Please tell me your race or ethnic background so we can review the treatment patients receive and make sure that everyone gets the highest quality care.”

2. Government recommendation

“Several government agencies recommend that we collect information on patients’ race and ethnic background. The state will use this information to make sure all patients get high quality health care. Please tell me your race or ethnic background so we can help the state reach this goal.”

3. Needs assessment

“We take care of patients from many different backgrounds. Please tell me your race or ethnic background so we can understand more about the patients we serve. This will help us

ensure the best services possible. That is why we ask everyone about their race, ethnicity, language and disability.

- We ask these questions of everyone. The information will help us make sure we provide the best services to everyone.
- We want to make sure all our patients get the best care possible. We would like you to tell us your race, ethnicity, language and disability background so we can review the treatment all patients receive. We want to make sure everyone gets the highest quality of care ([HRET 2007](#)).

Messages above use a “quality monitoring” approach where the goal is to make sure that everyone gets the highest quality care. This approach is based on several studies by Baker and colleagues (Baker et al., 2005; 2007). The goal of this type of message is to:

- Increase comfort, and
- Reduce the non-response rate.

Examples of what **not** to say or communicate include:

- “I’m asking you these questions because the government says I have to.”
- “This will help us hire staff to better meet **your** needs.”
- “This will help us make sure **you** get the best possible care (or services).”

train our staff better and improve our health education materials.”

4. **Personal gain**

“Please tell me your race or ethnic background. We want to make sure all our patients are treated equally. This will help make sure that you always get the best care possible.”

5. **Data privacy**

“We want to make sure all our patients get the best care possible. We would like you to tell us your race or ethnic background, so we can review the treatment that patients receive and make sure everyone gets the highest quality care. *Only a few people here will be able to see this information. The doctors and nurses caring for you will not be given this information.*”

Findings indicated that respondents felt more comfortable in providing information meant to improve quality. This was either directly in terms of needs assessment approach, or indirectly in terms of quality monitoring. They felt least comfortable in providing information because of a personal gain or government recommendation. The type of needs assessment may matter, however. In a previous study, the needs assessment approach (which indicated the information will also help hiring decisions) was not found to be effective (Baker et al., 2005).

In addition, it is important to state that the information is confidential:

The only people who see this are registration staff and administrators. Also, people who work in quality improvement and oversight. Your privacy is protected by law ([HRET 2007](#)).

It is important to make sure people who collect the data understand the importance of the messaging. Also, that they follow data system collection protocols.

Messaging about disability and functional limitations

We recommend adding some messaging in the Disability section to increase the comfort of the respondents (see REALD template for an example). This is because the disability questions for the first time and they will be new to most people. Also see here for a “[Response matrix](#)” (in the disability section). It provides more guidance on messaging specific to disability.

Mode and format of data collection

The format of the data collection tool may differ based on the mode of data collection. For example, web-based surveys can display main headings of racial and ethnic categories. When someone selects the heading, a drop-down menu then displays choices to select all that apply. Keep in mind this works well when people know where to find their primary racial or ethnic identity under commonly used federal OMB categories. On paper forms, however, “all at-a-glance” racial and ethnic categories may be easier to process.

Order of questions

The REALD template is just a template. You can change the order of the data sections and questions, such as language, as you need to for each program. However, you cannot change the content of the questions and response items. Note, the language and disability questions were ordered to facilitate skip patterns. If your population is over the age of 15, OEI suggests placing the activity limitation question at the end.

We recommend you format questions so the respondent easily sees the question and all response choices at once (e.g., on the same page of a paper survey). This helps the respondent feel comfortable. It also supports data accuracy. This may also help reduce misclassification due to a person who does not see the best choice and chooses among only what they see.

To ensure REALD questions are accessible to all, language questions (for service-based systems) should be first in the data collection process. This may be difficult

to do depending on mode, format and space limitations. For instance, on the paper-based template of REALD, the question about alternate formats is before the race and ethnicity section. The rest of the language questions are on the next page. Clients, members or participants may be more used to seeing questions about their race and ethnicity. Thus, they may feel more comfortable answering those first. Then, they can move onto possibly less-familiar questions about language, followed by disability.

Scripts and prompts

When the mode of data collection is by phone or by personal interview, we recommend that you use scripts. Examples are those used by the [Centers for Disease Control and Prevention \(CDC\) for the BRFSS to standardize](#) the process. We also recommend you use the sections on demographic questions in the interview guide published by the [Census for the Current Population Survey \(CPS\)](#) to guide development of the script. In particular, [Chapter 3, section Q](#) of the Interview's Manual provides excellent guidance for when and how to probe when asking the disability questions. Following this guidance will result in data quality similar to that of the Census.

Standardized drop-down lists using a person-centered approach

A drop-down coding table does not always have to be visible to the respondent, particularly if data collection is in person. When you collect data directly from the person, you can take a person-centered approach without showing or listing all categories. Rather, you can ask open-ended questions for a person to self-identify. Once a person self-identifies, you can use a trauma-informed approach to repeat the person's response. This verifies with the person that you heard them correctly. You can then transfer the information to the most suitable category in the data system. It is ideal to have a fill-in option where you can store information that does not clearly fit into a category. For example, you would select "Other Asian" if someone said, "Southeast Asian." You would then write in the note field to store the text "Southeast Asian."

Skip patterns and validity checks in electronic data systems

Primary race or ethnic identity

If you collect data electronically, consider using skip patterns when you administer these questions. That way, the person does not have to review all the racial categories again. Also, consider showing only categories previously selected to those who indicate they have more than one racial or ethnic identity.

Age of respondent – implications for language and disability questions

If REALD data will pertain to individuals under the age of 15 (e.g., Oregon Health Plan application collects information about children) as well as adults, you will want to build in skip patterns for date of birth (if collected already). Otherwise, you can add a question **before** the language and disability questions. There are two age categories that determine whether questions are asked or not:

1. These questions are **not** asked if the child is under the age of five
 - a. How well do you speak English?
 - b. Do you have serious difficulty walking or climbing stairs?
 - c. Because of a physical, mental, or emotional problem, do you have serious remembering, concentrating, or making decisions?
 - d. Do you have difficulty bathing or dressing
2. These questions are **not** asked if the person is under the age of 15
 - a. Because of a physical, mental, or emotional problem, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?

One way to build in skip patterns is ask for month and year of birth, or add a two-part question such as:

- Are you or the person you are filling this out for under the age of 15? (yes, no, or unknown)
 - » If yes, another question pops up:
 - ◇ Are you or this person under the age of five? (yes, no, or unknown)

Age when acquired disability

If you are using or plan to use a drop-down list for the age follow-up question, we suggest using a drop-down list that begins with:

- Don't know
- Don't want to say
- Since birth, and
- After birth and before age 1. (Followed by numbers from 1 to 100 or so.)

Further, you can apply some validity rules when you develop the electronic data collection tool. First, make sure the date of birth or current age is matches the sample population. If you know everyone is 18 and older, then the date of birth or current age should reflect that. When a person enters an acquired age, it should be equal to or before their acquired age. You should build a validity rule for this. For example, if someone says they acquired the condition at age 60, but their current age is 50, then you could ask that person to recheck their answer.

Language

If you use the two language questions specified in the OARs (Do you need an interpreter? Do you need a sign language interpreter), consider if someone were to state a need for both. Ask the person to confirm if they need both a spoken language interpreter and a sign language interpreter. In rare cases there may be a need for both types of interpreters.

Also, note that sometimes a deaf person may require two types of sign interpretation:

1. A Certified Deaf Interpreter (CDI) who will interpret from the person's sign language to American Sign Language (ASL), and
2. An ASL interpreter who will interpret from ASL to English.

It is important to not restrict the person from identifying only one type of sign interpretation.

Building in functionality (in service-based data systems)

To ensure linguistic access and effective communication, it is good to consider how to use all the responses to the language questions:

- Alternate format
- Preferred spoken and written language, and
- Interpreter needs and English proficiency

This can prompt follow-up. For example, if one were to say “yes” to the need for written materials in an alternate format, ask:

- How will this information be communicated to the case manager?
- Who will contact the person and how?
- How will you make sure all written communications to be sent out in this format?

Design in advance to make these questions work. This ensures linguistic access and effective communication. It may be a big step in reducing inequities among those with limited English proficiency. Also, for those who require alternate formats for written materials.

To be inclusive and accessible, OEI suggests the below sign language interpreter and other communication access options for Deaf or deaf and hard of hearing people:

- [American Sign Language Interpreter \[ORS 185.110\]](#)
- [Deaf Interpreter for Deaf-Blind and Deaf with additional barriers](#)
- [Communication Access Realtime Translation \(CART\)](#)
- [Assistive Listening Systems and Devices \(ALSs or ALDs\)](#)

Consider availability of bilingual staff. If a person says their preferred spoken language is other than English and indicates need for an interpreter (or sign language interpreter), consider the addition of another question. For example, “Would it be OK for us to match you to a bilingual case manager speaking (their preferred language)?” Such a question improves the language question and helps streamline the process.

Data systems (tools)

The data collection tool design is based in part by how the data will be stored and vice versa. For example, “Do you want to have pull-down tables of spoken and written languages for language questions?” This may or may not be possible. This section provides some tools and resources that may be helpful.

Using standardized coding schemes

It is good to consider coding schemes and tables already in data systems you use. This will help you decide how to construct drop-down tables or lists such as a list of preferred written languages. For example, if you expect to receive data from health care providers you may want to consider adoption of the [45 CFR 170.207](#) specific vocabulary standards for race and ethnicity from the CDC ([CDC Race and Ethnicity Code Set Version 1.0](#)). Similarly, the standard for preferred language is within the [ISO 639-2](#) 45 CFR 170.207 (g)(1). [Standards for sexual orientation and gender identity](#) are outlined in 45 CFR 170.207 (o)(1).

Mapping REALD to other data collection standards

Mapping REALD to the CDC race and ethnicity code set

There are over 900 race and ethnicity codes in the CDC Health Level 7 (HL7) Code Set introduced in 2000 so look for this item REALD and CDC Race and Ethnicity Cross-Map (Code Set Version 1.0) at: <https://www.oregon.gov/oha/OEI/Pages/REALD.aspx>. As stated in the seminal IOM report, “In formulating this set, the CDC worked with HL7 (Health Level Seven International) and X12, the leading standards-setting organizations for data interactions and for administrative transactions, respectively” (Ulmer et al., 2009, p. 77).

Mapping to OMB standards

Office of Management and Budget ([OMB](#)) uses standards for race and ethnicity. Data reported to other agencies, such as the federal government, may need to be rolled-up into the OMB standards for race and ethnicity. See [Table 10](#) for more information on mapping REALD response categories to the OMB categories. See [here](#) for information on aggregating race and ethnicity data using OMB standards.

Table 10: Race and ethnicity crosswalk: OMB standard categories and REALD

REALD racial and ethnic identity standards	OMB standards	HHS standards (federal surveys)
American Indian Alaska Native Canadian Inuit, Métis or First Nation Indigenous Mexican, Central or South American	American Indian or Alaska Native	American Indian or Alaska Native
Asian Indian Chinese Filipino/a Hmong Japanese Korean Laotian South Asian Vietnamese Other Asian	Asian	Asian Indian Chinese Filipino/a Japanese Korean Vietnamese
African African American Caribbean Other Black	Black or African American	Black or African American
Guamanian or Chamorro † Micronesian, Marshallese or Palauan* Native Hawaiian Samoan Tongan* Other Pacific Islander	Native Hawaiian or Pacific Islander	Guamanian or Chamorro Native Hawaiian Samoan Other Pacific Islander
Middle Eastern ‡ North African ‡ Slavic Eastern European Western European Other White	White	White
Latinx or Mexican Latinx or Central American Latinx or South American Other Hispanic or Latinx	Hispanic or Latino/a	Mexican, Mexican American, Chicano/a Another Hispanic, Latino/a or Spanish origin

* Categories are in the benefit system for OHP (ONE), but not official REALD categories. In REALD, Hispanic and Latinx categories are in one question, not two questions (ethnicity) as in the OMB standard or in the HHS standard.

† It is strongly recommended that these categories are separated in data collection and reporting, if cell sizes permit.

‡ Note: Middle Eastern and North African (MENA) are listed in the “White” category in both the REALD OARs and the OMB and HHS Standards. However, we strongly recommend grouping these two categories in their own MENA parent group in both data collection and reporting. That way those who identify as Middle Eastern and or North African who don’t identify as White have these choices available.

IDEAS checklist 1: Designing the data collection tool

Inclusion (and equity in process)	Dignity	Equity (as a result and an outcome)	Accessibility	Intersectionality
Did you avoid inequitable exclusion of the population of interest from design features and the decision-making process?	<p>Do all parties effected by REALD data standards (including data collectors) share in decision-making?</p> <p>Did you make it so that those most effected by REALD data standards can fully participate?</p>	<p>Does the data collection tool work?</p> <p>Can the data be used as intended? For example, clean data, not incomplete, etc.</p> <p>Did you make the data or reports accessible and easy to understand?</p>	<p>Did you design the data collection tool with accessibility in mind?</p> <p>Did you needlessly exclude anyone (due to disability, language, etc.)?</p> <p>Does the tool engage well those who:</p> <ul style="list-style-type: none"> • Use non-verbal communication • Have cognitive impairments, or • Have learning disabilities? <p>Do you need extra resources to ensure accessibility?</p>	<p>Does the data tool work for intersectional analyses later?</p> <p>Did you consider “hidden” subgroups (e.g., refugees with disabilities) in the development of the data collection tool?</p>

Notes. See [here](#) for more information about the IDEAS decision aid.

IDEAS checklist 2: Collecting data

Inclusion (and equity in process)	Dignity	Equity (as a result and an outcome)	Accessibility	Intersectionality
<p>Did you target outreach to have equitable representation in the data?</p> <p>Did you consider oversampling of small subgroups?</p>	<p>Did you intentionally build trust and rapport?</p> <p>Did you also give information about the benefits of giving this data?</p> <p>Did you use trauma-informed practices in the procedures?</p>	<p>Did you make sure there will be equitable representation in the data?</p> <p>Did you minimize unknown and missing data?</p>	<p>Did you make the survey, form and process ADA accessible? Did you make them accessible in different languages?</p> <p>Did you use plain language? Did you make the form or survey easy to read?</p>	<p>Did you make sure you collect data from those most likely to be “hidden” in the margins (e.g., refugees with disabilities)?</p>

Notes. See [here](#) for more information about the IDEAS decision aid.

5. Data quality, analyses and reporting

This chapter emphasizes the importance of checking data quality. High-quality data depicts the real-world construct of the concept it measures (Baškarada & Koronios, 2014). Efforts to quantify, monitor, understand and reduce inequities in health care are dependent on collection of high-quality data that support analyses. Implementing REALD standards in data collection tools is just the first step. It will be important to conduct periodic data quality checks to:

- Ensure high quality, reliable, timely and complete data
- Identify high rates of incomplete data, outliers and discordance, and
- Refine the process of data collection.

Using REALD to improve data quality

Unknown, decline and missing data

There are non-response which allow respondents to state they:

1. Don't know or unknown, or
2. Don't want to answer or decline to answer.

These are active non-responses instead of skipping the question. Respondents now have two response choices to frame their response. This should reduce the amount of missing REALD data. When it is not possible to add validation rules to ensure completeness of data, such as paper surveys, an option for data entry could be added. An example of this is, "Did not answer." This will help to explain why there is missing data.

It is important to ensure that missing data for any of the REALD questions are not missing at random. Checking missing patterns may reveal a pattern in the missing data. For example, how the data was collected, by whom and other variables collected at the same time (for more information please see Baraldi & Enders, 2010; Little & Rubin, 1989; UCLA: Academic Technology Services & Statistical Consulting Group).

Checking for outliers and discordance

You can use responses to REALD questions to identify several data quality concerns.

This includes:

- Respondent data quality issues
- Site of data collection data quality and collection issues, and
- Mode of data collection data quality differences.

Identifying outliers may help in finding opportunities to improve data quality with training. It can also be helpful to compare responses reported by the U.S. Census Bureau or American Community Survey data.

Responses to REALD questions can also be used to identify discordance at the individual level. Periodic checks on what is written in open fields compared to checked boxes allows us to identify parallelism in the response. See Table 11 for suggested strategies, using REALD data collection standards, to identify discordance at the individual level.

Table 11: Data quality checks using REALD

Compare responses on the left to those on the right	
Open-ended race and ethnicity questions	Other race and ethnicity questions
Affirmative to alternate format	Disability questions
Affirmative to need for sign language	Disability questions
“Not well” or “not at all” to English proficiency	Affirmative to need for interpreter
Age of an acquired functional limitation or condition	Age is younger or the current age

Identifying emerging populations

Responses to open-ended questions for race and ethnicity, as well as the “other” category may help to identify emerging subpopulations. There are several situations which could require use of the “other” category.

Analyses and reporting

The nature of disparity research is such as it is not easy to collect the data. Often the group experiencing inequities is relatively small and thus does not have as much visibility. For this reason, REALD categories and questions shall not be omitted in the data collection process. This is true, even if the expected number in a subgroup is thought to be so small that it will be difficult to report the disaggregated data.

REALD reporting requirements

Below is a summary of reporting requirements:

- HB 2134 does not require new reports; rather the focus is to enhance existing stakeholders reports that contain demographic information.

- Try to address challenges in sample sizes before you suppress data or roll-up data categories. There are analysis challenges that relate to small sample sizes and the reliability of data. These are inherent in health disparity research (Okazaki & Sue, 1995). There are [strategies](#) to implement to address many of these challenges.
- Generate publicly available data* using REALD data categories as much as possible. However, this must be done without violating the privacy of individuals in the dataset.†
- Be sensitive to constituent concerns about potential misuse or abuse of when you make reports. Include information on the validity and reliability of the data, if available.

We recognize there are times when it is necessary to aggregate. For example, when required to report data using standards set by funders or policy makers (such as the OMB and HHS standards). Likewise, when there is a need to compare data to other data sets using aggregated categories such as the OMB categories or the HHS categories. The decision to aggregate fully to five, six, or fewer racial or ethnic categories needs to be looked at in context. The decision should be made based on the situation. See [Table 10](#) for a cross-walk of REALD racial and ethnic identity categories to OMB standards, as well as HHS Standards for federally-sponsored surveys.

Many OHA datasets are required to aggregate to OMB standards when reporting to most funders, such as the CDC. However, we are not limited to reporting data locally at a more granular level. We should disaggregate to our own reports as much as possible. **Disaggregation of data using REALD categories is a core underlying principle of REALD legislation.** Routinely aggregating data into broader categories before reporting out would defeat the purpose of the legislation (HB 2134). Therefore, as much as possible, per the **REALD Implementation Policy, REALD data shall be reported and disseminated using the REALD data categories** while still protecting the privacy of individuals represented in each dataset. The exception to this is reporting of data directly to funders who require use of OMB or HHS standards.

Suppressing or aggregating data categories

A researcher may have concerns about reporting using the REALD categories due to:

- Statistically unreliable data
- Misinterpretations of the data, or
- Privacy concerns.

* Generally, data provided has been processed by OHA staff (it is not “raw” data).

† It is beyond the scope of this policy to determine which data are made public or not.

If so, the researcher must follow procedures in the REALD Implementation Policy to ask for an exemption in routine reporting of REALD data for the public.

You must try to address challenges associated with small sample sizes before you suppress data or roll-up data categories. There may be challenges due to the research design, especially with culturally specific groups. However, it is important to consider how the conventional focus on large samples and randomization “might be incongruent with local epistemologies and cultural understandings of how the knowledge to inform prevention is generated and standards of evidence are established” (Etz & Arroyo, 2015).

Intermediate aggregation

Refer to the [OHA Public Health Division’s guidelines](#) for how to handle small cell sizes in reporting. There are times when it is necessary to aggregate due to small cell sizes that could violate confidentiality. Likewise, when doing otherwise may provide a misleading interpretation of the data. However, before suppressing data in reporting, consider aggregating to the lowest level possible before small cell sizes become an issue. To do this, consider the context and lived experiences of people associated with social and health inequities.

Contextual factors may influence the lived experiences of members of certain groups in ways that shape exposure to adverse social and health outcomes. Examples are:

- Geography
- Histories
- Language
- Immigration patterns (including resources and supports from country of origin), and
- Acculturation.

As noted in a seminal report from the Institute of Medicine, “different ways of aggregating multiracial categories may be appropriate for different purposes; therefore, the subcommittee does not endorse any single analytic approach but concludes that, whenever possible, each race an individual selects on a collection form be available for analysis” (Ulmer et al., 2009, p. 74).

Similarly, there are different ways of combining subcategories. How to go about this needs to be seen in context in terms of:

- The work itself
- Outcomes of interest, and

- Ideally, how communities would like to be represented in the data when there are limitations due to cell sizes.

For example, Van Dyke and colleagues (2016) described how they collaborated with five American Indian communities in Washington, Idaho and Montana. They did so to learn about and develop criteria to use in aggregating tribal health data in a meaningful way. The collaboration resulted in the development of five criteria for aggregation:

1. Access to resources and services
2. Geographic proximity
3. Type of community (e.g., urban or rural)
4. Exposure to environmental contaminants, and
5. Economic development (of the tribe).

Another strategy is to examine literature about the outcome of interest or contextual factors associated with the outcome (such as diabetes). After combining groups, it's good to examine how and to what extent the outcome of interest (e.g., prevalence of diabetes) changes because of aggregation. Avoid masking potential inequities that could occur with aggregation. There are other resources that can help inform these types of decisions. Examples of such resources are:

- The [Racial Heterogeneity Project](#), and
- A report from PolicyLink: [Counting a Diverse Nation: Disaggregating Data on Race and Ethnicity to Advance a Culture of Health](#)

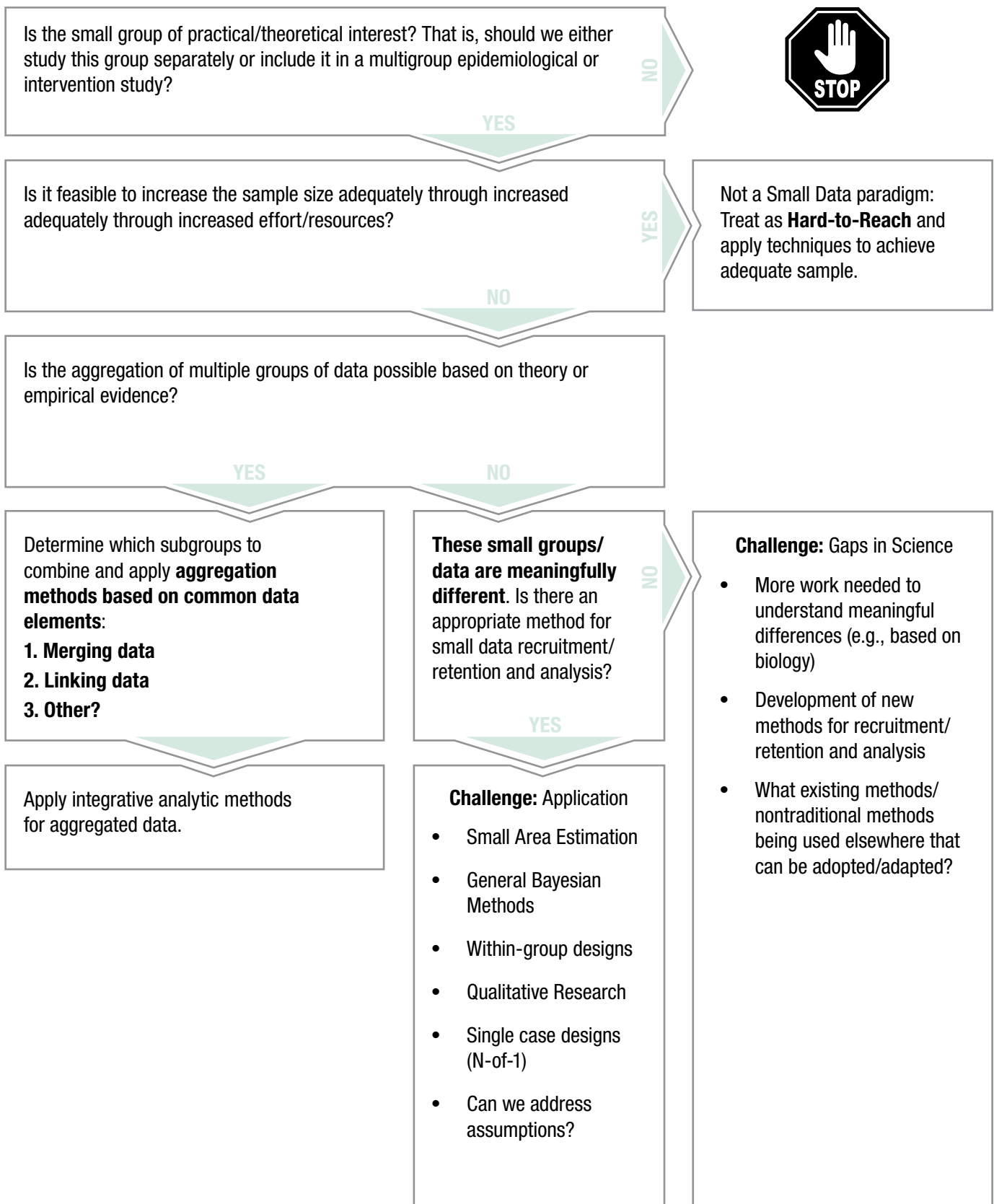
Additional strategies and flowchart to address the challenges of small sample sizes

Srinivasan and colleagues provide a flowchart that can be used to identify and address challenges associated with small sample sizes (see [Figure 6](#)) (2015). See [here](#) for resources to address these challenges.

“Although small sample sizes generally reduce the statistical reliability of inferences, all else being equal, a little information about an understudied ethnic minority with large health inequities is better than none at all. ... exploratory research using initial findings can open up fruitful questions for more systematic research and justify the allocation of resources.”

(Wong et al., 2012, p. 17).

Figure 6: Research with Small Data: Identifying challenges.



Source: Srinivasan et al., 2015. Reprinted with permission.

Race and ethnic specific analyses – some considerations

Reporting using the primary race category

You can use the response from the primary race and ethnic identity question instead of relying on a “multi” option for everyone to create unduplicated counts. Note that you may still have a “multi” category, however, for those you stated they did not have just one primary identity.

Types of analyses and reporting using REALD

Alone verses alone or in combination* (AOIC)

The **maximum number of people** that report a racial or ethnic identity is reflected in the race alone or in combination (AOIC) concept. This represents the **number of times responses in one “parent” race category,† either:**

- **Alone,** or
- **In combination with the other parent race categories.**

For example, a respondent who indicated Chinese *and* Western European would be counted in the Asian alone or in combination category as well as in the White alone or in combination category. Therefore, the **sum** of all race **alone or in combination** categories **equals** the **number of races reported** (i.e., identities). The number of all races reported will exceed the total population reported. Using the *alone* count rather than the *alone or in combination* count significantly undercounts these populations. Counting people is not the only purpose of collecting data on race or ethnicity. OHA is also interested in looking at the relative experience of social and health inequities. The AOIC count exceeds the total population and the proportion will be more than 100 percent. However, AOIC counts offer the maximum count of a given population and *does not risk an undercount of a specific population*. Yet, using the AOIC method *can dilute the experience of people who identify as primarily one group*. For example, the health status of American Indians alone vs. American Indians alone or in combination may be very different.

* This text, the AOIC concept and the following paragraph (about AOIAC), with minor edits, was reprinted with permission from Valerie Steward (2017) from [Analytics for Race and Ethnic Data](#).

† The “parent” categories usually align to the current OMB categories: American Indian or Alaska Native (AIAN), Asian, Black or African American, Native Hawaiian or other Pacific Islander (NHOPI), AND White. In some cases, the parent group may include Middle Eastern and North African.”

Example: AOIC with REALD disability categories

The AOIC approach can be used with the disability categories as well. See [Table 12](#) for an example of reporting disability using the ***alone and in combination*** approach. In this example, someone who is deaf-blind would be counted twice under “Hearing,” and again under “Vision.” If you wanted to know the number of people by functional limitations such as mobility or hearing, the alone or in combination approach works well.

Alone or in any combination (AOIAC)

The ***alone or in any combination*** (AOIAC) concept is used when there are **tallies of detailed groups within a major race group**. For example, the total Asian alone or in any combination population is a tally of **all** detailed Asian **responses**, rather than the **number** of Asian **respondents**. Respondents reporting several Asian groups are counted several times. A respondent reporting “Korean” and “Filipino” would be included in the Korean as well as the Filipino numbers. This number represents the **maximum** number of people reporting in any of the detailed Asian groups. For more information about implementing race AOIC and race AOIAC in practice, see [Analytics for Race and Ethnic Data](#). As with AOIC approach, counting people is not the only purpose of collecting data on race or ethnicity. OHA is also interested in looking at the relative experience of social and health inequities.

Example: AOIAC with REALD racial and ethnic identity categories

Figure 7 provides an example of a type of AOIAC visual of new OHP members enrolled between Sept. 1, 2017, and June 30, 2018. This visual is helpful to see not only how enrollees self-identified, but also to see how the response options are being used. For example, 85% of all enrollees who identified as White used the “Other White” option.

Table 12: People with disabilities in Oregon, alone or in combination

	No.	%
Deaf or have serious difficulty hearing		
Does not have this disability	3831701	95.2
This disability only	95101	2.4
2+ disabilities	98325	2.4
Total	4025127	100
Blind or have serious difficulty seeing, even when wearing glasses		
Does not have this disability	3921248	97.4
This disability only	32768	0.8
2+ disabilities	71111	1.8
Total	4025127	100
Have serious difficulty walking or climbing stairs*		
Does not have this disability	3495692	92.2
This disability only	87840	2.3
2+ disabilities	209590	5.5
Total	3793122	100
Have serious difficulty remembering, concentrating, or making decisions*†		
Does not have this disability	3544566	93.4
This disability only	81496	2.1
2+ disabilities	167060	4.4
Total	3793122	100
Have difficulty dressing or bathing*		
Does not have this disability	3676692	96.9
This disability only	2732	0.1
2+ disabilities	113698	3.0
Total	3793122	100
Have difficulty doing errands alone such as visiting a doctor's office or shopping †‡		
Does not have this disability	3100178	93.7
This disability only	17259	0.5
2+ disabilities	190264	5.8
Total	3307701	100

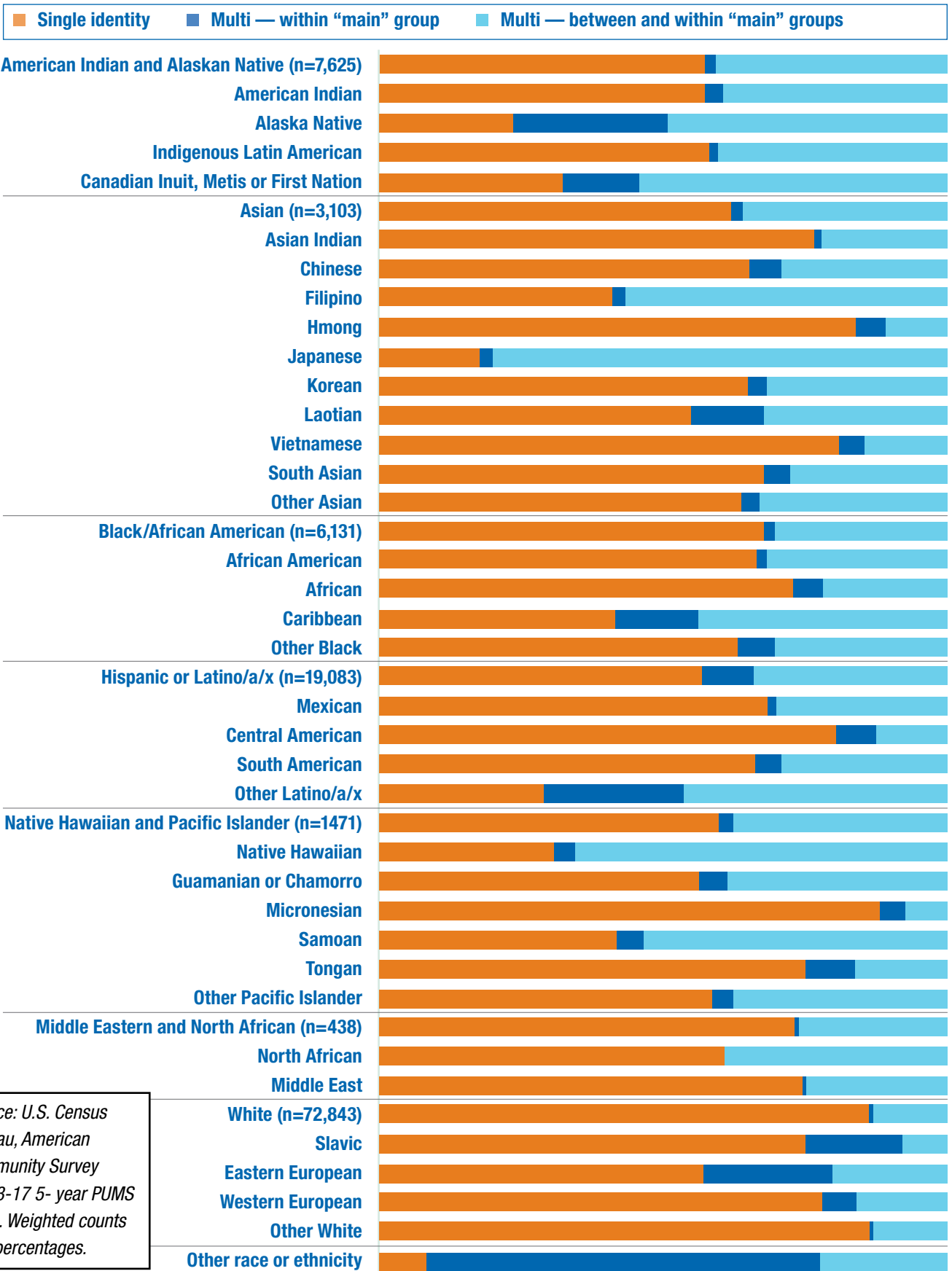
Source: U.S. Census Bureau, American Community Survey (2013-17 5- year PUMS data). Weighted counts and percentages.

* Ages 5 +

† Question begins with: "Because of a physical, mental, or emotional condition do you have"

‡ Age 15+

Figure 7: Racial ethnic identities: alone and in combination (% , all ages)



Source: U.S. Census Bureau, American Community Survey (2013-17 5- year PUMS data). Weighted counts and percentages.

Imputing primary race

Sometimes you may need to impute primary race for those who indicating having two or more identities but did not answer the primary race question. In these cases, you could use a “most identify and rarest group first” method where you apply an algorithm to assign those with multiple identities to one primary race (Mays, Ponce, Washington, & Cochran, 2003). For example, those who identify both as Western European and African American would be assigned to the African American subgroup. In another example, one would be coded as MENA (Middle Eastern and North African) if they reported being North African and South Asian. Further, they would be coded as MENA when you create a composite aggregate racial or ethnic identity variable without duplicate counts. To determine the rarest group rank order, consider the population of interest. Decide the level of population you are trying to address -- statewide, county level or regional. For example, using ACS 2013-2017 PUMS data, the order rarest to most common racial or ethnic groups for Oregon statewide using aggregated categories is:

- Native Hawaiian and Pacific Islander
- Middle Eastern and North African
- Black or African American
- American Indian and Alaska Native
- Asian
- Latinx
- White

There are other ways of imputing primary race. May, Ponce, Washington and Cochran (2003) provide a foundation to understand complexities that come when people get to pick more than one race in the Census and other large health surveys. Lee, Satter and Ponce (2009) examined how different racial classifications changed survey weights (in Census surveys) and health related indicators for California’s AIAN. Both grounded their work in public health. They also illustrated the importance of being transparent about methods used and being able to justify them. Both provide a good model of how to be thoughtful in deciding which approach to take.

Estimating granular racial and ethnic denominators using American Community Survey

The ACS PUMS data provides three race variables and two ethnicity variables with different degrees of detail. Some response options are specific such as Japanese, Alaska Native, American Indian, Chinese and so on. In these cases, the response

options translated directly to a REALD race and ethnicity response option. Some variables are coded more generally, such as AIAN, and Pacific Islander. Imputation of specific REALD granular racial and ethnic identities, using the general response options, was made using **ancestry, language and place of birth**, when appropriate. See [Table 13](#) for more information. This approach can be replicated using other datasets if there is enough information to impute granular categories such as those listed above in bold.

Table 13: American Community Survey imputation methodological notes

	Birth place	Ancestry	Language	Notes
American Indian and Alaska Native (AIAN)				
American Indian		✓	✓	
Alaska Native				
Indigenous Mexican, Central or South American		✓	✓	Mexican, Central and South America
Other Indian (Including Canadian Inuit, Metis or First Nation)				All others who identified as AIAN. Note that ACS data did not provide a way to identify those who may identify as Canadian Inuit, Metis or First Nation.
Asian				
Asian Indian	✓	✓	✓	Asian Indian, Bengali, East Indian, Punjabi
Chinese	✓	✓	✓	
Filipino	✓	✓	✓	
Hmong		✓	✓	
Japanese	✓	✓	✓	
Korean	✓	✓	✓	
Laotian	✓	✓	✓	
Vietnamese	✓	✓	✓	
South Asian	✓	✓	✓	Bangladesh, Bhutanese, Burmese, Maldivian, Myanmar, Nepal, Pakistani, Sri Lanka
Other Asian	✓	✓		All others who identified as Asian.
African American or Black				
African American	✓	✓		Born in the United States and identified as black or African American.
African	✓	✓	✓	African countries
Caribbean	✓	✓	✓	Caribbean and identified as black
Other Black	✓	✓		All others who identified as black

	Birth place	Ancestry	Language	Notes
Hispanic or Latinx				
Mexican	✓	✓		
Central American	✓	✓		
South American	✓	✓		
Other Latinx				All others who identified as Hispanic.
Native Hawaiian and Pacific Islander				
Native Hawaiian	✓	✓	✓	
Guamanian or Chamorro		✓	✓	
Micronesian,* Marshallese or Palauan.	✓	✓	✓†	Chuukese, Kosrae, Marshallese, Micronesian, Palauan, Pohnpei, Yapese.
Samoan	✓	✓	✓	
Tongan	✓	✓	✓	
Other Pacific Islander				All others who identified as Pacific Islander.
Middle Eastern and North African				
Middle East	✓	✓	✓	Afghanistan, Bahrain, Cyprus, Iran, Iraq, Israel, Jordan, Kuwait, Lebanon, Oman, Palestine, Qatar, Saudi Arabia, Syria, Turkey, United Arab Emirates, Yemen
North African	✓	✓	✓	Algeria, Egypt, Libya, Morocco, North African not specified.
White				
Slavic	✓	✓	✓	Bosnia and Herzegovina, Bulgaria, Belarus, Czech Republic, Croatia, Macedonia, Montenegro, Poland, Russia, Serbia, Slovakia, Slovenia, Ukraine.
Eastern European	✓	✓	✓	Albania, Armenia, Azerbaijan, Estonia, Georgia, Hungary, Latvia, Lithuania, Moldova, Romania.
Western European	✓	✓	✓	Andorra, Austria, Azores Islands, Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Liechtenstein, Luxembourg, Malta, Monaco, Netherlands, Norway, Portugal, Spain, Sweden, Switzerland, England, Scotland, Ireland, United Kingdom.
Other White				All others who identified as white.

Notes. All categories used available race and ethnicity information in the American Community Survey (2013-2017 PUMS data). Place of birth, ancestry and language information was used only if the person identified within the main racial or ethnic identity group, such as Asian, Hispanic, White, or Black or African American.

* This category was intended to include those affected by the Compact of Free Association (COFA). This includes the Federated States of Micronesia (Yap, Chuuk, Pohnpei and Kosrae), Palau and the Marshall Islands.

† Languages associated with this category include: Carolinian, Chuukese, Mokilese Ngatikese, Pingelapese, Pohnpeian, Mapia, Mortlockese, Namonuito, Pááfang, Puluwatese, Satawalese, Sonsorolese, Tanapag, Tobian, Ulithian and Woleaian.

Primary race and multiracial identities

There is value in allowing persons to self-identity without being limited to one primary race. OHA also suggests allowing multiracial identity if chosen in response to a question of primary racial or ethnic identity. In other words, multiracial identity when self-reported by the person answering REALD questions should be preserved. In these cases, you would retain the multiracial group identity instead of imputing primary racial or ethnic identity. Doing this is in line with results from a [2015 Pew Research Center survey](#) which found that of the 6.9 percent of persons reported more than one race, or based on race of parents and grandparents) would be considered multiracial. See [Figure 8](#) for a breakdown by multiracial subgroups of the 39 percent who identified as multiracial. Below is an excerpt from the Pew report that helps to understand the significance of multiracial identity:

“... when asked, “Do you consider yourself to be mixed race or multiracial, that is, more than one race, or not?” a substantial majority of Americans with a background that includes more than one race (61%) say that they do not consider themselves to be multiracial. When asked why they don’t identify as multiracial, about half (47%) say it is because they look like one race. An identical proportion say they were raised as one race, while about four-in-ten (39%) say they closely identify with a single race. And about a third (34%) say they never knew the family member or ancestor who was a different race. (Individuals were allowed to select multiple reasons.) This multiracial “identity gap” plays out in distinctly different ways in different mixed-race groups” (Pew Research Center, 215, p. 12).

Considerations of disability specific analyses

It is important study responses to disability questions in context. Consider if it makes sense to conduct analyses based on:

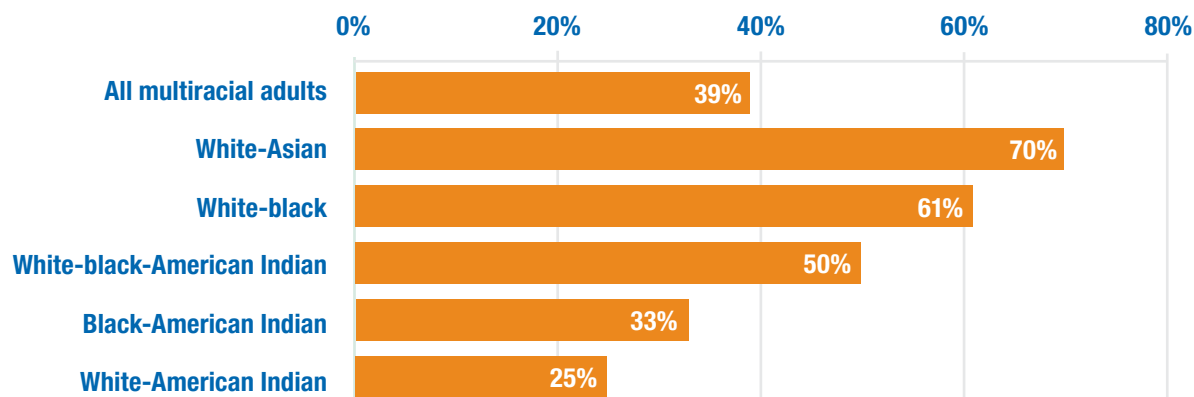
- Each disability type separately, or
- Combinations of disabilities for each person.

For example, consider results from two sets of analyses to determine, compared to non-disabled persons, who are more likely to be unemployed in Oregon. [Table 14a](#) below illustrates the variation in unemployment by types of functional limitations. The odds of persons with a hearing loss being unemployed is 1.8 that of persons without a hearing loss. Those with a self-care difficulty or independent living limitations were more likely to be unemployed than those without these limitations.

Figure 8: Multiracial identities

4-in-10 have mixed-race background and say they're multiracial

% of adults with a background including two or more races who consider themselves "multiracial"



Note. Based on adults with two or more races in the backgrounds of self, parents or grandparents. Multiracial subgroups are non-Hispanic and mutually exclusive. Sample sizes are: 118 white-black, 88 white-Asian, 907 white-American Indian, 128 black-American Indian, 106 white-black-American Indian.

Source: Pew Research Center survey, February 6-April 6, 2015 (n=1,555 multiracial adults)

However, as just over half of Oregonians with disabilities of any age have just one functional limitation, these analyses do not consider the different lived experiences among people who reported a hearing limitation. For example consider the differences in attaining employment among those who are deaf-blind vs those who are deaf/hard of hearing and have mobility limitations, vs those who are deaf/hard of hearing and do not report any other limitations.

For those reasons it may be worthwhile to create a **composite or profile variable** to learn more about who is more likely to be unemployed since many people with disabilities report two or more disabilities. In the example below, using Census data, a composite variable with seven subgroups was created based on relatively high overlap of persons with more than one disability. The first subcategory included only non-disabled people. See [Table 14b](#) for the rest of the categories.

Results, using the composite disability variable, reveals the diversity among people with disabilities. It is important to consider nuances associated with having one limitation compared to another, and in what combination. The results displayed in [Table 14b](#) generally report lower odds of being unemployed for all those with just one limitation. Also, for those who have two or more limitations excluding self-care or

independent living limitations. The odds of being unemployed was greatest for those with multiple disabilities involving difficulties with self-care (dressing, bathing) or independent living (doing errands alone).

Table 14a: Odds of being unemployed by disability type

Disability type*	Adjusted odd ratio	Standard error	95% Confidence intervals	
			Lower bound	Upper bound
Deaf or hard of hearing	1.8	0.11	1.61	2.02
Blind or low vision	2.3	0.16	2.05	2.68
Mobility disability	4.8	0.22	4.35	5.23
Cognitive difficulty	3.9	0.20	3.58	4.35
Self-care difficulty	6.2	0.56	5.19	7.37
Independent living difficulty	6.3	0.39	5.56	7.08

* Reference group: people not reporting any limitations.

Source: U.S. Census Bureau, American Community Survey (2013-2017 5-year PUMS data). Age 18-64. Excluded non-civilians and people living in institutions from analyses. People classified as unemployed here includes those unemployed (looking for work) and those not in the labor force within the last five years. Separate logistic regressions conducted for each disability type. The reference group is those without that disability. Adjusted for current age, race or ethnicity, gender, English proficiency, educational attainment and rural or urban. All odd ratios were significant at $p < 001$.

Table 14b: Odds of being unemployed by disability profile

Reference group- non-disabled	Adjusted odds ratio	Standard error	95 percent confidence intervals	
			Lower bound	Upper bound
Deaf or hard of hearing only	1.4	0.1	1.18	1.64
Blind or low vision only	1.6	0.2	1.31	1.91
Cognitive only	3.0	0.2	2.67	3.48
Mobility only	3.0	0.2	2.67	3.45
2+ disabilities	3.7	0.3	3.19	4.23
Self-care or independent living	6.5	0.4	5.79	7.23

* Reference group: people not reporting any limitations.

Source: U.S. Census Bureau, American Community Survey (2013-2017 5-year PUMS data). Age 18-64. Excluded non-civilians and people living in institutions from analyses. People classified as unemployed here includes those unemployed (looking for work) and those not in the labor force within the last five years. Adjusted for current age, race or ethnicity, gender, English proficiency, educational attainment, and rural or urban. All adjusted odd ratios were significant at $p < 001$.

Intersectionality using REALD as an analytic tool

Acknowledging the existence of multiple intersecting identities is an initial step in understanding the complexities of health inequities for populations from multiple historically oppressed groups. The other critical step is recognizing how systems of privilege and oppression that result in multiple social inequalities (e.g., racism, heterosexism, sexism, classism) intersect at the macro social-structural level to maintain health inequities (Bowleg, 2012, p. 1267).

Using REALD to further our understanding of health inequities requires an intersectional approach. This approach is in line with Bowleg’s compelling article featured in the American Journal of Public Health about intersectionality as a framework for public health (2012). Using an intersectionality lens in health disparity research provides a unique way to identify interactions between different types of discrimination (Sen, Iyer, & Mukherjee, 2009). OEI encourages you to use REALD data to implement an intersectional lens. This will help you analyze how the intersections of different identities impact health equity or equity in general. This section begins with a brief overview of intersectionality. It then moves onto how to use the REALD data in an intersectional manner. This approach should help you to better identify and address persistent health inequities.

Intersectional-like thought is not a very new phenomenon as illustrated by Hancock (2016). However, it wasn’t until 1989 that the term “intersectionality” was coined by Crenshaw (1989). Since then there has been a multitude of texts on intersectionality. The term “traveled” from the realms of critical race theory and feminist black studies to other disciplines. (See for example: Davis, 2008 (Sociology); Cole, 2009 (Psychology); Dhamoon, 2011 (Political science); Bowleg, 2012 (Public health); and Weber & Parra-Medina, 2003 (Women’s health). Consequently, the meaning and use of “intersectionality” may differ slightly as seen in these excerpts:

The term intersectionality references the critical insight that race, class, gender, sexuality, ethnicity, nation, ability, and age operate not as unitary, mutually exclusive entities, but as reciprocally constructing phenomena that in turn shape complex social inequalities (Collins, 2015, p. 2).

...intersectionality considers the interaction of such [race, gender, class and sexual orientation] as organizing structures of society, recognizing that these key components influence political access, equality, and the potential for any form of justice (Hancock, 2007, p. 64).

Intersectionality is a theoretical framework that posits that multiple social categories (e.g., race, ethnicity, gender, sexual orientation, socioeconomic status) intersect at the micro level of individual experience to reflect multiple interlocking systems of privilege and oppression at the macro, social-structural level (e.g., racism, sexism, heterosexism) (Bowleg, 2012, p. 1267).

Most definitions of intersectionality, focus on the experience of those holding multiple non-dominant social identities or categories. The goal is to identify and address the effects of multiple systems of oppression. This focuses attention on differences not only between groups, but also within groups. In addition, it aligns well with the purpose of REALD data collection standards. The robust nature of the REALD categories:

- Enhances our capacity to identify those most likely to experience certain health inequities,
- Helps our understanding of intersecting systems of oppressions. Also, how they operate to maintain health and social inequities.

Example of intersectionality: population by disability among those with limited English proficiency

A local organization wanted to learn more about refugees with disabilities in Oregon using the ACS data. See [Table 15](#) for an example of a relatively simple intersectional approach that was used to provide information. The organization now can explore further to discern needs and inequities.

Example of intersectionality: odds of unemployment by disability and race

An intersectional approach was used to examine the likelihood of being unemployed by race and disability using ACS data. There can be big differences in employment rates by “severity” of disability. This cannot be measured by ACS data. Therefore, a variable reflecting the severity of disability was created. For that variable, the number of disabilities was used. To keep it manageable, race was aggregated to three categories (White, Hispanic and Other). After that, following the guidance from Sen and colleagues (2009), an inter-categorical variable was created with 12 values (see [Figure 9](#)).

Reflections: Intersectionality and social location

It is important to look deeper at the lived experiences of those with intersecting subordinate identities. In addition, to consider how risk of exposure to adverse experiences such as discrimination is a function of context and social location. Social location refers “to the relative amount of privilege and oppression that individuals possess on the basis of specific identity constructs, such as race, ethnicity, social class, gender, sexual orientation, age, disability, and faith” (Hulko, 2009, p. 48). The relevance of social location of persons with regards to REALD is that social location is complex, fluid, and dynamic, changing with the social context (Hulko, 2009). For example, a study of the relationship between disability status and peer victimization found likelihood of peer victimization within the last 30 days increased with the addition of subordinate identities such as sexual orientation. These patterns in exposure to peer victimization varied based on the specific status (McGee, 2014). Yet, the relative magnitude of exposure to peer victimization could not be “characterized as additive or multiplicative (“double jeopardy” or “triple jeopardy”), as the type of non-dominant and dominant culture status is more informative than the number of non-dominant statuses held by the student” (2014, p. 21).

Table 15: People with limited English proficiency in Oregon by disability

	No.	%
Deaf or serious difficulty hearing		
Does not have this disability	214170	96.9
This disability only	2787	1.3
2+ disabilities	4066	1.8
Total	221023	100
Blind or have serious difficulty seeing, even when wearing glasses		
Does not have this disability	212876	96.3
This disability only	3489	1.6
2+ disabilities	4658	2.1
Total	221023	100
Have serious difficulty walking or climbing stairs*		
Does not have this disability	3495692	92.2
This disability only	87840	2.3
2+ disabilities	209590	5.5
Total	3793122	100
Have serious difficulty remembering, concentrating, or making decisions*†		
Does not have this disability	212148	96.0
This disability only	1841	0.8
2+ disabilities	7034	3.2
Total	221023	100
Have difficulty dressing or bathing*		
Does not have this disability	215073	97.3
This disability only	300	0.1
2+ disabilities	5650	2.6
Total	221023	100
Have difficulty doing errands alone such as visiting a doctor's office or shopping †‡		
Does not have this disability	189888	95.3
This disability only	1054	0.5
2+ disabilities	8324	4.2
Total	199266	100

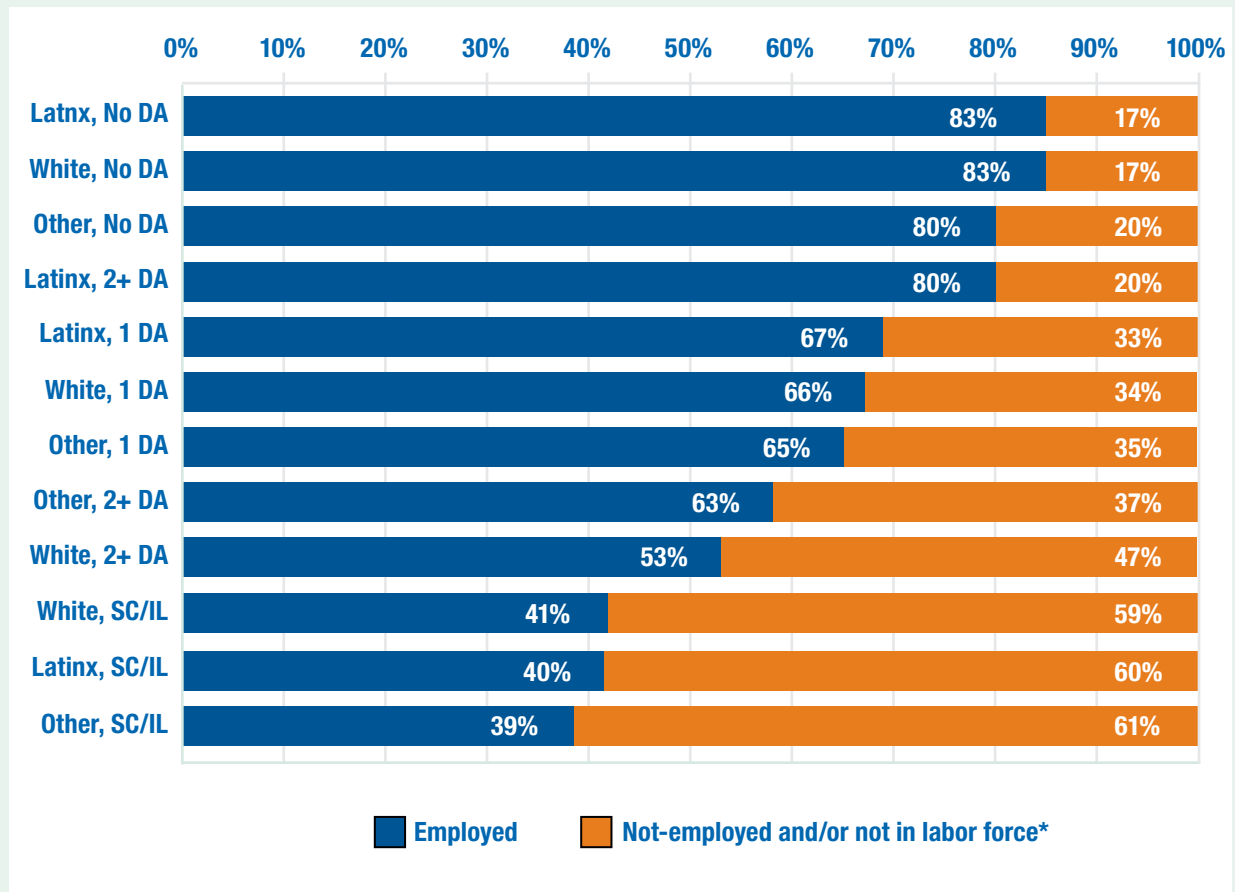
Source: U.S. Census Bureau, American Community Survey (2013-17 5- year PUMS data). Weighted counts and percentages.

* Ages 5 +

† The question begins with: "Because of a physical, mental, or emotional condition do you have"

‡ Age 15+

Figure 9: Employment Status by Disability and Race/Ethnicity



Source: U.S. Census Bureau, American Community Survey (2013-17 5- year PUMS data). Weighted percentages. N = 2,181,056, age 18-64, non-institutionalized civilians. DA = Disability; Latinx is used to be inclusive of all genders; SC/IL = self-care and or independent living difficulties.

Another example is taking the same data and running a logistical regression to understand the likelihood of being unemployed by the intersections of race or ethnicity and disability (Table 16). These results may help you think about efforts to increase workforce diversity. Interestingly, the adjusted odd ratios were not much different from that of Table 14b above with respect to disability profile. Compared to White non-disabled people:

- Latinx people without disabilities were less likely to be unemployed, and
- All other groups were more likely to be unemployed.

Disability appears to be the primary determinant of unemployment for people with disabilities. Post-hoc Wald tests did not reveal differences by race and ethnicity for those:

- Without disabilities

- With 2+ disabilities, and
- With self-care or independent living disabilities.

Still, significant differences were found however by race between Latinx with one disability and other people of color with one disability.

Table 16: Odds of being unemployed by intersections of race or ethnicity and disability

Ref group White, non-disabled	Adjusted odd ratios	Standard error	95% Confidence intervals	
			Lower bound	Upper bound
Latinx, no disability	2.3	0.10	2.12	2.51
Latinx, 2+ Disabilities	4.1	0.30	3.57	4.76
Other, no disability	6.4	0.44	5.55	7.27
Latinx, 1 disability	0.8	0.04	0.75	0.90
White, 1 disability	2.0	0.23	1.62	2.53
Other, 1 disability	1.2	0.40	0.63	2.32
Other, 2+ disabilities	6.3	1.53	3.88	10.12
White, 2+ disabilities	1.3	0.04	1.21	1.38
Latinx, Self-care and/or Independent Living	2.6	0.32	2.05	3.33
White, Self-care and/or Independent Living	3.7	0.86	2.32	5.81
Other, Self-care and/or Independent Living	7.9	1.41	5.59	11.25

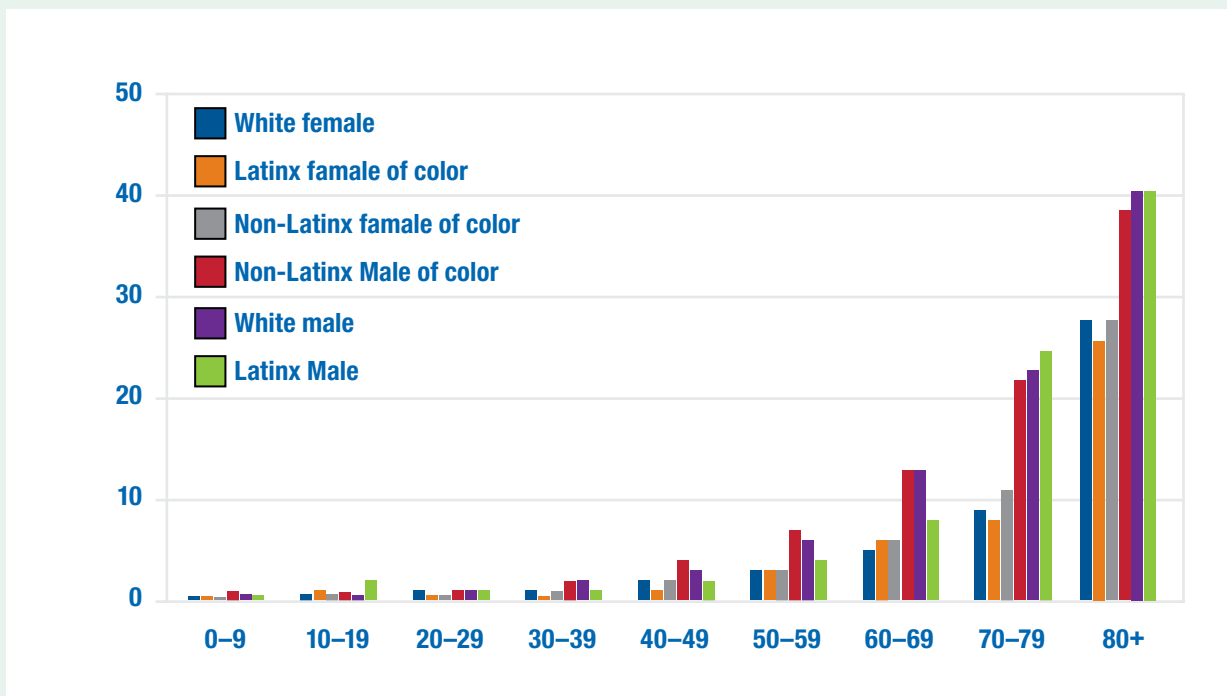
Notes. N = 2,181,056. Source: U.S. Census Bureau, American Community Survey (2013-2017 5-year PUMS data), ages 18-64. Unemployed included those not working (and looking for work) and those not in labor force (but worked within the last 5 years). Excluded individuals institutionalized or active in the armed forces. Adjusted for current age, gender, English proficiency, educational attainment, and rural/urban. Odd ratios sorted from low to highest. Compared to white non-disabled people, all other groups were found to have significantly different odds of being unemployed at $p < .001$ except for Latinx with 2+ disabilities.

Example of intersectionality approach: deaf and hard of hearing persons by race and gender

A deeper dive can be made within a specific subgroup using an intersectional approach. For example, a community-based organization advocating for people with hearing loss may want to know the age distribution of persons who are deaf or have serious difficulty hearing by race and gender. An analysis using ACS data (2013-2017 five year estimates) suggest some differences in proportion of Deaf (or deaf) and hard of hearing people by both race and gender (see [Figure 10](#)). For example, while eight percent of Latinx men ages 60-69 reporting having serious difficulty hearing, compared to 13 percent of all other men; 25 percent of Latinx men ages 70-79 reported having serious difficulty hearing compared to 22-23 percent of all other men. Post-hoc analyses of deaf and hard of hearing individuals age 70 and older, confirmed that, compared to Latinx females, all males were most likely to report

being Deaf (or deaf) or hard of hearing, with White males most likely to report being Deaf (or deaf) or hard of hearing (AOR = 3.2 [2.04, 5.11]), followed by Latinx males (AOR = 3.1 [1.63, 5.86]) and other males of color (AOR = 2.9 [1.75, 4.84]) were more likely to report being Deaf (or deaf) or hard of hearing, controlling for educational attainment, marital status and age. This type of information could inform outreach. In addition, perhaps some future qualitative inquires to understand more about the possible causes of higher rates of hearing loss among all men age 70 or older.

Figure 10: Age distribution of deaf/hard of hearing Oregonians by race/ethnicity and gender (percentage)



Source: U.S. Census Bureau, American Community Survey (2013-17 5- year PUMS data). Weighted percentages. Latinx is used to be inclusive of all genders .

IDEAS checklist 3: Sharing and reporting the data

Inclusion (and equity in process)	Dignity	Equity (as a result in outcome)	Accessibility	Intersectionality*
<p>Do you have a transparent process to provide external stakeholders the data they request?</p> <p>Do you send updates to your mailing list of organizations with a link to data on the state's website?</p> <p>Do you consider multiple forms of dissemination? If so, do you engage with community partners to do this?</p> <p>Was your analysis informed by contextual factors and the underlying meaning of REALD categories?</p>	<p>Do you have a process to involve the requester to understand why if the request for data are perceived inappropriate or not feasible? Do you also have alternate data sources to provide to the requestor?</p> <p>Can you address any concerns about misinterpreting data by increasing the capacity of community organizations to engage with data? (such as offering some training or focused technical assistance to community organizations) <i>(This generate more meaningful inclusion in use of the data.)</i></p>	<p>Will the report reflect diverse populations? Will it include those most impacted by the outcome of interest?</p> <p>Do you have a summary to highlight major results and on how to obtain the full results?</p> <p>Will the report help community identify and address health inequities?</p> <p>Will community partners be able to access the report based on the REALD data?</p>	<p>Do you have a central location on a program or state website where reports on data are posted? Did you make sure the website is ADA accessible?</p> <p>Do you use plain language used as much as possible? Do you have a table summary in narrative format if you use tables?</p> <p>Do you provide a notice of how to obtain the report in alternate formats? Are data available in alternate formats upon request?</p> <p>Do you save a PDF report as a readable PDF? Is the report accessible in different languages?</p>	<p>Do findings include information about those most impacted by the outcome of interest?</p>

Notes. See [here](#) for more information about the IDEAS decision aid.

6. REALD data collection resources

REALD paper-based survey templates

REALD questions are available in a pre-formatted template. Please see [here](#) for more information about these templates and associated links to the different versions and translation.

IDEAS decision aid

Checklists in this implementation guide (designing the data collection tool, collecting the data, sharing and reporting the data) were developed based on the IDEAS (Inclusion, Dignity, Equality, Accessibility and Intersectionality) decision aid. ([See chapter 6 and 8 within the IDEAS publication for more information.](#)) This decision aid was designed specifically to develop interventions to improve the health of people with disabilities (Berghs, Atkin, Graham, Hatton, & Thomas, 2016). This decision aid centers on the inclusion of people with disabilities in public health in the United Kingdom. However, it can be used in general for all groups who experience health inequities. It can also be used as an aid in thinking about REALD data collection processes. The IDEAS decision aid has five key elements:

1. **Inclusion** (and **equity** in the inclusion process) means inclusion of diverse populations and subgroups. There are three forms of exclusion to consider:
 - » **Active** exclusion is intentional and explicit. An example is excluding individuals under the age of 18 in the BRFSS survey.
 - » **Passive** exclusion is based on design features. One example is a lack of access for people with limited English proficiency. Another example is inaccessible web surveys.
 - » **Partial** exclusion is similar to active. However, those seen as problematic are excluded. An example is excluding those with mental health disabilities from participating in a survey.

Inclusion means not excluding persons from certain groups. It entails changing how things are typically done. Inclusion means ensuring active participation. This includes ensuring participation is meaningful, and not in a token way. For example, efforts to help community members (such as through training or

focused technical assistance) to engage with data will enable more meaningful inclusion in using the data.

2. **Dignity** is associated with self-determination, and sharing power and decision-making.
3. **Equity** (in outcomes) means considering the kind of short- or long-term impact there will be in changing health inequities.
4. **Accessibility** is more than just a checkbox. It means intentionally being accessible to those who need access. It also means considering a broader range of accessibility. Examples are providing compensation and childcare by time and place.
5. **Intersectionality** means considering people as having multiple identities, language needs and functional limitations.

Other resources for data collection

Toolkits and compendiums

- Centers for Medicare and Medicaid Services published a 2019 [Compendium of Resources for Standardized Demographic and Language Data Collection](#). It includes a variety of links to training tools, webinars and other resources. These can assist large organizations in collecting race, ethnicity, language and disability demographics.
- The Health Research and Educational Trust developed a [toolkit](#) to assist health care organizations with collection of race, ethnicity and language data.

External webinars

- The [Inequities Solutions Center](#) at Massachusetts General Hospital has several [webinars](#) relevant to collection of race, ethnicity and language (REAL) data. Webinars range from how to collect data to developing strategies to address inequities.

External reports and guides

- [Creating Equity Reports: A Guide for Hospitals](#)
- [Legality of Collecting and Disclosing Patient Race and Ethnicity Data](#)
- [Resources for Developers of Quality Reports for Consumers](#)

7. REALD and community engagement

Community engagement and the IDEAS decision aid to guide community engagement

The [core values of OHA](#) underlying the work we do include:

- Health equity
- Services excellence
- Integrity
- Leadership
- Partnership
- Innovation
- Transparency

These values are congruent with REALD and OHA's commitment to engage with those most impacted by health inequities. However, it can be difficult to put OHA's values into practice when it comes to community engagement. Unless we are intentional about how we do this. The [Community Engagement Strategies Checklist](#) may be helpful to engage equitably with community members/groups. The checklist is intended for OHA staff use. However, it may be helpful in other settings.

As a general guideline, research to help identify and address health inequities should be informed by community priorities and customized to priority populations. Researchers may want to conduct key informant interviews with trusted leaders in communities most impacted to determine the priorities of the communities. It is also important to work with community members to create research questions that ensure the information will be relevant and meaningful. A way to operationalize equity in research partnerships involving community organizations is through:

- Community-based participatory research (CBPR), and
- Use of popular education.

The IDEAS (Inclusion, Dignity, Equality, Accessibility and Intersectionality) decision aid provides a starting place for upholding values of health equity and partnership. Below is a collaborating checklist specific to REALD and OHA of use in guiding community engagement. Programs are encouraged to expand on this collaborating checklist as makes sense for their partnerships.

IDEAS checklist 4: Collaborating with community partners

Inclusion (and equity in the inclusion process)	Dignity	Equity (as a result / in outcome)	Accessibility	Intersectionality*
<p>Is there a process to address and avoid inequitable exclusions of diverse community partners?</p> <p>Are power imbalances between state- and community-based organizations acknowledged and addressed?</p>	<p>Is there shared decision-making with all parties impacted?</p> <p>Is there recognition and value that the data belongs to the public?</p>	<p>Are REALD data used to identify and address health inequities?</p> <p>Are the data useful?</p>	<p>Is plain language used as much as possible?</p> <p>Do you use the Community Engagement Strategies Checklist?</p>	<p>Do community partners include those most impacted at the intersections (e.g., people of color with disabilities)?</p>

Notes. See [here](#) for more information about the IDEAS decision aid.

Sharing data

Much of the data we collect at OHA and DHS are not used by our partners and communities most impacted by health inequities. We want to change that. The ultimate purpose of collecting REALD data is to identify and address health inequities. This can be achieved most effectively when both state agencies and community members are able to access and use these data. See this checklist pertaining to sharing the data with stakeholders.

Responding to data requests from community organizations

When community organizations or members request data, appropriate OHA staff should do what is possible to honor that request. The data we collect is not just for internal use. It is meant for the benefit of and use by community stakeholders. To help manage this, OEI suggests developing a criteria list to prioritize data requests. For example, it may be of prime importance to find out how the data will be used to benefit the community. Therefore, data for a community meeting to identify priorities or provide education would be a priority.

It is reasonable to have concerns about the potential misuse of the data. However, this should not be a reason to withhold data. Staff should provide education and consultation for community organizations and other external stakeholders. This way they can better understand the data and limitations of the data. Formal training is not necessary. It can be a conversation. Indeed, requests for data can best be approached as a conversation. In the conversation, state staff ask what data the

person or organization is interested in and why. Together, appropriate OHA staff and the stakeholder or organization determine the best data to match the needs.

Other important considerations:

- Person-level data should not be shared with external researchers without a data agreement in place, even with anonymous identifiers.
- Data should be reported out in the same categories as collected. This applies even if sample sizes are small.
 - » In exceptional circumstances, when sample sizes are too small to protect confidentiality, the data steward should:
 - ◇ Consult with the requestor.
 - ◇ Decide on the best way to deal with these limitations.
 - ◇ Consider the context of the data request.
 - ◇ Find if the chosen categories to collapse will still meet the requestor's needs. See [here](#) for more information.
- Sharing editable files with external researchers (e.g., comma-separated values, Excel) is best. This allows community organizations, local health departments and other stakeholders to more easily form their own graphics or otherwise determine how to best present the data.
- Consider giving a written a summary of the limitations of the data in the files shared. For example, you could state that the sample sizes are too small to generalize about broader population.

Addressing barriers for community members to access state data

In early 2017 staff from the Equity and Inclusion Division, in collaboration with community partners from Multnomah County Health Department, hosted five community meetings in Portland, Salem and Eugene. The purpose of the meetings was to guide prioritization of datasets for REALD. OHA also asked communities about barriers in accessing health data to improve the health of people in their communities. The list below is a summary of the most commonly identified barriers.

- Not knowing:
 - » What data is available;
 - » The type of data needed;
 - » Where to start;
 - » Whom to contact.
- Information being buried and hard to access

- Data of interest not being available.
- Cumbersome requirements such as separate data agreements needed for each data request (e.g., for county health department staff).
- Data tables provided in PDF format which then required manually recreating tables and charts in Excel.

We suggest:

- Working proactively to address these barriers by making it clear whom to contact for requests for data.
- Treating those who make requests respectfully.
- Engaging in conversation to help community members identify and access the data most relevant to their needs.

8. Community engagement resources

Resources for engaging with communities equitably

The [Community Engagement Strategies Checklist](#) is intended for Oregon Health Authority staff, but could be helpful in other settings.

Popular education

Popular education is method and philosophy of education and organizing rooted in social justice. There is evidence to suggest that popular education is:

- At least as effective as conventional, lecture-style education in increasing participants' knowledge.
- More effective than conventional education in increasing empowerment, skills and understanding (Wiggins, Hughes, Rodriguez, Potter, & Rios-Campos, 2014).

It recognizes all people know a lot based on their life experiences, regardless of education, occupation and other characteristics. Thus, it emphasizes starting with what people already know and building on that foundation, so people can solve problems and create more just communities.

According to [An Introduction to Popular Education](#) (Wiggins & Rios, 2007), some key principles are:

- The current distribution of the world's resources is unjust and change is possible.
- We learn with our heads, our hearts and our bodies.
- It is important to create an atmosphere of trust so that people can share their ideas and experiences.
- We all know a lot. As educators and organizers, we should always start with what people already know or do.
- Knowledge we gain through life experience is as important as knowledge we gain through formal education.
- People should be active participants in their own learning process. They should not be passive recipients.

- In each situation in which we try to teach or organize, the conditions should reflect the conditions of the society we are trying to construct. This means equality between “teacher” and “student,” and democratic decision-making.
- The purpose of developing a critical consciousness is to be able to act to change the world. (Critical thinking alone is not enough.)

Community-based participatory research (CBPR)

CBPR came from a focus on research with communities most impacted by the research. However, in any academic or governmental organization (such as OHA) partnering with the community issues of trust, inequities and power tend to be present. CBPR addresses equity in the partnership. Key aspects of CBPR involve:

- Co-learning and reciprocal transfer of expertise among the research partners
- Shared decision-making, and
- Mutual ownership (Viswanathan et al., 2004).

Israel and colleagues identified nine key principles of community-based participatory research that support successful research partnerships (Israel, Schulz, Parker, & Becker, 1998, pp. 178-180). These principles are summarized below:

1. Recognizes community as a unit of identity.
2. Builds on strengths and resources in the community.
3. Facilitates collaborative, equitable involvement of all partners in all phases of research.
4. Integrates knowledge and intervention for the mutual benefit of all partners.
5. Promotes a co-learning and empowering process that attends to social inequalities.
6. Involves a cyclical and iterative process.
7. Addresses health from both positive and ecological perspectives.
8. Disseminates findings and knowledge gained to all partners.
9. Involves a long-term commitment by all partners.

For more information about these principles, see:

- [Skill-building curriculum from the University of Washington](#) (The Examining Community-Institutional Partnerships for Prevention Research Group, 2006).
- [Community-Campus Partnerships for Health](#) website (look under the INFO tab for more information and resources).

Both popular education and CBPR are valuable resources. Popular education makes it possible to perform CBPR with fidelity. It equalizes power dynamics that can occur in academic and community partnerships.

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Strategies associated with small sample sizes*

Data collection strategies

- Sampling
 - » Oversampling (Bilheimer & Sisk, 2008; Sue & Meenu, 2006).
 - » Respondent-driven sampling (Srinivasan et al., 2015).
 - » Adapting snowball sampling (Sadler, Lee, Lim, & Fullerton, 2010).
 - » Select related populations that are suitable “neighbors” (Korngiebel et al., 2015)
- Increase completeness of demographic data
 - » Mixed methods (Nguyen et al., 2014).
 - » Optimize study features that you can control (Hopkin et al., 2015).

* See References for strategies for full references cited in this section.

» Within-group design (Hopkin et al., 2015).

Strategies to increase sample size

- Pooling (Bilheimer & Sisk, 2008; Nguyen et al., 2014; Sue & Meenu, 2006).
- Data Linkages (Bilheimer & Sisk, 2008; Nguyen et al., 2014).
- Aggregation of multiple groups if can justify (Srinivasan et al., 2015).

Subgroup analyses

Etz & Arroyo, 2015; Fok, Henry, & Allen, 2015; Haegerich & Massetti, 2013; Henry, Fok, & Allen, 2015; Hopkin, Hoyle, & Gottfredson, 2015; Hoyle & Gottfredson, 2015; Korngiebel, Taulii, Forquera, Harris, & Buchwald, 2015; Supplee, Kelly, MacKinnon, & Barofsky, 2013

Modeling and estimation

- Multilevel and structural equation modeling (Nguyen et al., 2014).
- Statistical modeling for multilevel ordinal data (Hedeker, 2015).
- Small-area estimation (Shah, Russo, Earl, & Kuo, 2014).

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Appendix A. Reliability and validity of the ACS disability questions

Reliability and validity of the ACS disability questions Office of Equity & Inclusion, a division of the Oregon Health Authority Ritu Dhungana, Ph.D. and Marjorie McGee, Ph.D.

HB 2134 passed during the 2013 legislative session. This bill required DHS and OHA to develop data collection standards for Race, Ethnicity, Language and Disability (REALD). The REALD data collection standards were finalized in 2014 with intensive engagement with external and internal stakeholders, and were based on local, state, and national best practices.

To our knowledge, Oregon is unique in that two state agencies are required to collect disability as a demographic; to our knowledge, no other state requires a state agency to collect disability as a demographic. This is significant as health inequities between people with disabilities and non-disabled people are well-documented (See for example: Campbell, Sheets, & Strong, 1999; Lennox, Beange, & Edwards, 2000; McGee, 2014, p. 4; Turk, Scandale, Rosenbaum, & Weber, 2001; Wisdom et al., 2010). Collecting information on disability allows for health and human service data to be analyzed and reported by disability as a demographic so that avoidable health inequities can be identified and addressed. For example, results from the Behavioral Risk Factor Surveillance System (BRFSS) survey conducted in 2015 suggest that Oregonians with disabilities were more likely to smoke, to have diabetes and be overweight; Oregon women age 50 or older were less likely to receive a recent mammogram ([OODH, 2015](#)).

The purpose of this paper is to provide a background of six of the seven REALD disability questions derived from American Community Survey (ACS),* and how

* The ACS is an annual survey conducted by the U.S. Census Bureau that collects and reports on demographic, social, economic, and household data (Erickson, 2012). The following six disability questions are currently included in the ACS:

1. Are you deaf or do you have serious difficulty hearing?
2. Are you blind or do you have serious difficulty seeing, even when wearing glasses?
3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, understanding, or making decisions? (For clients/respondents ages 5 and older)
4. Do you have serious difficulty walking or climbing stairs? (For clients/respondents ages 5 and older)
5. Do you have difficulty dressing or bathing? (For clients/respondents ages 5 and older), and

well these questions work in terms of validity (identifying people with disabilities as intended) and reliability.

Background and development of the ACS disability questions

The purpose of the ACS disability questions is to identify the population of persons with disabilities with a minimum set of questions.* Members of federal interagency work group brought together in 1997 by the Office of Management and Budget agreed that four domains (vision, hearing, mobility, and cognitive functioning) identified most people with disabilities. These four domains were represented in four questions that focused on functional limitations. The reason for the focus on functional limitations in the disability is aptly captured by Altman (2014):

Because the science has not yet identified valid and reliable measures of environments that limit participation, the closest we can come to identifying the population that has the potential to be limited in participation is to identify those with functional limitations that may or may not be accommodated environmentally. These are the persons we identify as being at risk, but whose outcomes are uncertain without the environmental component of the measurement, which should include not only the physical environmental barriers, but also those associated with attitudes of others (Altman 2014, p. 4).

The independent living question (doing errands alone such as visiting a doctor’s office or shopping), and the self-care question (being able to dress and bathe oneself) were intended to assist agencies in planning for, and providing services help people participate equitably as much as possible in society (Brault et al., 2007).

Accordingly, the responses to the ACS disability questions provide “an acceptable estimate of the population of persons with disabilities, as defined by a person’s risk of participation limitation when he or she has a functional limitation or impairment” (Brault et al., 2007, p. iii). Further, the ACS disability questions were intended to be “a subjective measure based on respondents’ calculations and ultimate determination of what constitutes a report-able impairment” (Miller & DeMaio, 2006, p. 7). This can be seen in the examples given by Miller and DeMaio of how people with hearing loss responded to the question about “serious trouble hearing; either very conservatively (“not being able to hear a fire engine going past you”), or very liberally (“need people ‘to sometimes speak up’”) (p. 9-10).

The development and testing of the disability questions used by the Census Bureau began in the 1990’s; the first-time demographic disability questions were used in

6. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor’s office or shopping? (For clients/respondents ages 15 and older).

* The maximum number of questions was set at six in 1997 by an interagency work group convened by the Office of Management and Budget. The six questions also needed to align with the ADA and meet the needs of different agencies collecting disability as a demographic (Brault, Stern, & Raglin, 2007).

the Census 2000 sample survey (U.S. Census Bureau, 2014). In 2003, the disability questions in the ACS were changed due to a commitment to “clarify the intent of the question” (Stern & Brault, 2005, p. 3). The current demographic disability questions in the ACS, last changed in 2008, underwent in-depth cognitive and content testing of the ACS questions in 2006, described in detail below.

Testing the ACS disability questions

Cognitive testing

Respondents’ answers to survey questions are necessarily based on personal experience and perceptions of that experience. Therefore, it is impossible to altogether avoid respondent subjectivity and obtain an entirely objective picture of disability status. In their response, respondents may incorporate a variety of differing factors including their age, health status, sense of independence, whether or not they perceive themselves as having a problem, whether others have told them that they have a problem, and whether they need help or use an assistive device. In this regard, it is unfeasible to develop questions that yield a perfect measure of disability; disability statuses, as they are derived from survey questions, are subjective statuses that are grounded in respondents’ perceptions and interpretations.

The method of cognitive testing, however, provides insight into the types of potential response errors so that egregious errors can be fixed and so that decisions can be made to determine what, if any, errors will be tolerated to generate the best statistics. Additionally, the method provides a better understanding of both the strengths and weaknesses of the data (Miller & DeMaio, 2006, p. 3).

In 2004 members of the ACS working group from the National Center for Health Statistics and US Census Bureau collaborated to conduct in-depth cognitive testing on the ACS disability questions (Miller & DeMaio, 2006). Sixty-nine adults with and without various health conditions as well as physical, mental health, physical, learning disabilities and temporary injuries participated. Researchers conducted the testing via mail, telephone, and personal visits. The first interview round resulted in a set of changes to the disability questions that were subsequently tested in the next round of interviews; five rounds of interviews were conducted.

Cognitive test findings. The cognitive testing revealed how slight changes in word choice resulted in different interpretations; in some cases, changing the wording compromised the original intent of the disability questions. For example, the original intent of the inclusion of “usually” in some of the questions was to indicate a long-term condition more than six months, but interpretations by participants varied; in one case a participant interpreted “usually” as “ever”, and in another case a participant interpreted “usually” as “often” (Miller & DeMaio, 2006). As a result, the attempt to discern and distinguish long-term from short-term conditions by using the word “usually” was dropped.

In several questions the word “serious” was added to include “critical, activity-hindering problems” (Miller & DeMaio, 2006, p. 22). However, deciding whether the functional limitation is “serious,” or whether one has difficulty concentrating or remembering, appeared to be influenced by the participant’s age. For example, older participants indicated they said “no” to the cognitive question because it is normal aspect of aging. The term “serious” was also found to limit how participants answered the self-care and independent living questions. Consequently, not all of the questions include the term “serious.”

In another example of how the wording and word order matters, the activity of “making decisions” was added to the cognitive question, not because this was an actual cognitive activity of interest, but because it conveyed a level of severity implicated by the question (Miller & DeMaio, 2006).

Concerning the question designed to capture independent living limitations, participants interpreted the “go-outside-home alone” question to refer to access to transportation, which was not the intent of the question. The final independent living question (“Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor’s office or shopping?”) was found to work well, particularly with an example of an errand placed at the end of the sentence.

Participants had difficulty understanding the question about work limitations – even with different versions tested. There was also some misreporting (e.g., saying they did not have a work limitation but were receiving disability payments). Thus, the question about work limitations was not included in the final set of disability questions.*

Content testing

Following cognitive testing, content testing of the disability questions was conducted with over 60 thousand residential addresses in the U.S. Some participants answered the ACS survey containing the 2006 disability questions (control group), and others answered the ACS survey containing the revised questions (test group). Participants (if successfully contacted in the follow-up process) were re-interviewed with the same set of disability questions again, as well as some detailed questions about their functional limitations. For example, participants were asked additional questions such as whether they used a hearing aid and how difficult it was to hear with and without the

* Burkhauser and colleagues (2014) suggested that a work limitation questions be added to the set of ACS disability questions so as to include all persons receiving income support. However, Altman and colleagues (2017) did not find support for the concern; in their study based on NHIS data from 2011, they tested to see if the ACS data was able to capture individuals with SSI/SSDI benefits. They found that having the work limitation included increased the population only by 1.4% and did not change the makeup of the groups. They concluded that the six ACS disability questions resulted in unbiased estimates and were representative of the major conditions/ impairments and limitations associated with disability while conforming to the space, reliability and validity requirements of the Census” (p. 6).

hearing aid. In this way, researchers were not only able to assess reliability, but also use the detailed questions to assess the congruence in responses.

The content testing did three things:

1. Determine if the revisions improved reliability of the revised disability questions
2. Certain participant's understanding of the disability questions by examining responses from both the set of six questions, and the detailed follow-up questions on functioning, and
3. Determine if the revised questions better identified people with disabilities.

Content test findings. The revised set of disability questions resulted in significantly lower nonresponse rates. The nonresponse rate for individuals not answering any of the disability questions was low (2.7 percent), compared to the percentage of participants who did not answer at least one disability question (5 percent). The nonresponse rate was lowest for those indicating a hearing (3 percent) or vision disability (3.2 percent), and slightly higher for those indicating a mobility disability (4.4 percent), self-care disability (4.3 percent), independent living disability (4.3 percent), and cognitive disability (4.0 percent) (Brault et al., 2007).

The simple response variance rate (SRV) captures the random variation in the participant's response to the same question from the initial interview, and the follow-up interview. Based on the lower SRV rates for each revised test question, the revised disabilities questions demonstrated better reliability.

There were some variances in the underlying condition associated with the functional limitation by age of participants. For example, among individuals age 5 to 14 identified as having a cognitive limitation, ADHD was most frequently (55 percent) listed as causing the difficulty remembering, concentrating or making decision. However, among individuals age 15-64 identified as having a cognitive limitation, the most frequent reason was "Other" (38.9 percent), and among individuals age 65 and older identified as having a cognitive limitation, the most frequent reason was "mental retardation" (41.8 percent), followed closely by "Senility or Alzheimer's (38.7 percent) (Brault et al., 2007). These variances based on age and likely contextual differences across the lifespan highlight the importance of collecting the age of participants as well as the age the participant acquired a functional limitation.*

The revised set of disability questions lowered the prevalence of people with disabilities from 14.1 percent to 13.2 percent. This was largely due to the revision in the mobility question; the previous version the mobility question included upper

* For this reason, the REALD disability questions includes a follow-up question to each affirmative response: "At what age did this condition began?" This follow-up question is specific to REALD, not the ACS. Capturing age expands the ability of the analyst to create subgroups by age acquired functional limitation, length of time with a functional limitation, and to be able to control for length of time with a functional limitation.

mobility limitations (“reaching, carrying, or lifting”); the prevalence of people with mobility disabilities dropped to 6.9 percent from 9.4 percent (Brault et al., 2007).^{*} The detailed follow-up questions also demonstrated that those who answered affirmatively to a functional limitation question reported greater difficulty on specific tasks associated with the functional limitation. Based on these findings the revised disability questions appeared to do a better job of identifying the population of persons with disabilities (Brault et al., 2007).

Limitations

The number of participants in the cognitive testing was relatively small, with most being white, and having some college. The cognitive and content testing did not include participants without phone numbers, as well as those in living group homes, institutionalized, without housing. The initial survey (for the content testing) relied on mail forms, which can be difficult to answer if one has a vision disability, severe cognitive disability, or difficulty writing things due to a physical disability. If one did fill out the mail form, the initial content testing was conducted in person (with a computer), which reduces these types of barriers. In the follow-up interview testing, the phone was used to collect the data, which can be difficult for people with hearing disabilities, people with severe cognitive disabilities, and people with speech disabilities.

The ACS disability questions cannot be used to identify discrete subgroups within each of the four domains (cognitive, mobility, hearing, vision) captured. For example, the question capturing the cognitive domain does not distinguish between people with developmental disabilities and those with severe and persistent mental health disabilities.

Furthermore, the ACS disability questions may not account for cultural differences in how participants interpret the questions. The lack of translation into multiple languages aside from Spanish poses another limitation, as the meaning of the intent of the questions may be lost in translation (Brault et al., 2007).[†]

Conclusion

The reliability of the current version of the disability questions is better than the previous set. Based on the content testing, the ACS disability questions revised in 2008 worked well to identify people with functional limitations as a measure of people disabilities.

^{*} Upper mobility limitations were thought to be captured by the self-care disability – having difficulty dressing or bathing.

[†] The REALD Spanish language template, using the translation provided by the Census Bureau, is available from the Office of Equity & Inclusion.

However, it would be worthwhile to explore the comprehension and readability of these questions with people who may have been less likely to participate in the content testing: deaf and hard of hearing people, people with severe cognitive disabilities, and people with speech or communication disabilities.

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Glossary of terms and acronyms

Aggregate: When “aggregate” is used for race and ethnic identities it means broad information about a group of identities.

American Community Survey (ACS): ACS is an annual survey using random sampling to survey a smaller proportion of the population to derive population estimates. When appropriate, OHA uses weighted estimates derived from ACS (Public Use Microdata Sample (PUMS) of Oregonians).

Assisters: Application assisters are trained and certified to assist individuals in applying for:

- Medicaid (Oregon Health Plan or OHP).
- Children’s Health Insurance Program (CHIP).
- Qualified Health Plans (QHP).

Assisters have expanded access to client accounts via ONE. Assisters should never be designated as authorized representatives for their clients.

DHS: DHS is the abbreviation for the Oregon Department of Human Services. DHS is Oregon’s principal agency for helping Oregonians achieve well-being and independence through opportunities that protect, empower, respect choice and preserve dignity, especially for those who are least able to help themselves.

Disability: REALD collects data about functional limitations as demographic information. This “disability” information is not a medical diagnosis or for use in determining eligibility.

Granularity (subgroups): Granularity refers to the level of detail of data. Granular data provide more information than the aggregate or parent group data. For example, the broader Asian population consists of those who identify on a more granular level as Korean, Japanese, Chinese, Vietnamese, or other Asian ethnicities.

HB 2134: In 2013 the Oregon Legislature passed [House Bill 2134](#). The bill requires DHS and OHA to develop a standard for collection of race, ethnicity, language, and disability (REALD) data in conjunction with community stakeholders. The statutory authority for these rules is codified in ORS [413.042](#) and [413.161](#).

HHS: HSS stands for U.S. Department of Health and Human Services. HHS has its own [data collection standards for race, ethnicity, sex, primary language and disability status](#) used for all federally sponsored surveys such as ACS.

IDEAS checklists: The development of IDEAS checklists in this implementation guide (designing the data collection tool, collecting the data, sharing and reporting of the data – IDEAS Checklist 3: Sharing and reporting the data) were based on IDEAS (Inclusion, Dignity, Equality, Accessibility and Intersectionality) decision aid.

OARs [943-070-0000 thru 943-070-0070](#): OARs stands for Oregon Administrative Rules. The rules listed established uniform standards and practices for OHA and DHS to follow on the collection of data on:

- Race
- Ethnicity
- Preferred spoken or signed and preferred written language, and
- Disability.

OEI: Abbreviation for Office of Equity and Inclusion, an OHA office. OEI promotes health equity, diversity and inclusion for all Oregonians.

OHA: Abbreviation for Oregon Health Authority. OHA is a state of Oregon agency. OHA is at the forefront of lowering and containing costs, improving quality and increasing access to health care in order to improve the lifelong health of Oregonians.

OHP: Abbreviation for Oregon Health Plan. OHP is Oregon’s Medicaid or medical assistance program. It helps people with low incomes get access to care.

OMB: United States [Office of Management and Budget \(OMB\)](#). OMB developed minimum standards for race and ethnicity (Directive No. 15) for federal statistics and reporting.

ONE: ONE is the acronym for [Oregon Eligibility](#), Oregon’s online Medicaid application system. This system became fully compliant with REALD standards in June 2017. ONE is being updated to include most DHS programs (Integrated Eligibility). The updated version of ONE should roll out incrementally starting in 2020. DHS is integrating eligibility determination functionality into ONE for:

- Non-modified adjusted gross income (non-MAGI) Medicaid (Oregon Health Plan or OHP).
- Supplemental Nutrition Assistance Program (SNAP).
- Employment-Related Day Care program (ERDC).
- Temporary Assistance for Needy Families (TANF) program.

With these DHS program additions to ONE, applicants will have the same screens to collect REALD variables. This means the method to collect REALD variables from these programs will be uniform and consistent.

Parent group: See the term “aggregate” above. Within racial and ethnic identities, the “parent group” is the “main” category.

Race and ethnicity: Race typically refers to a physical characteristic such as skin color. Ethnicity refers to cultural factors such as nationality. In data collection efforts, “ethnicity” in the U.S. typically refers specifically to Hispanic ethnicity. Race typically refers to five or six categories, such as:

- White.
- Asian.
- American Indian and Alaska Native.
- Black or African American.
- Pacific Islander.


REALD: REALD stands for *Race, Ethnicity, Language, and Disability*. It refers to data collection standards developed to comply with [HB 2134](#) and described in OARs [943-070-0000 thru 943-070-0070](#).

Real-time captioning: Real-time captioning is also known as computer-assisted real-time transcription, or computer aided real-time transcription or [CART](#). Real-time captioning is a service like court reporting. It is a service in which a transcriber types what is being said at a meeting or event into a computer that projects the words on to a screen. This service can be provided on-site or remotely. It is especially useful for people who are deaf or have hearing loss but do not use sign language. See <https://www.ada.gov/effective-comm.pdf> for more information.

Stakeholders: This group includes individuals, groups, organizations, policy makers, contractors, providers, coordinating care organizations (CCO), and others who are affected by and/or can affect the REALD data collection standards. For the purposes of the REALD policy, **internal** stakeholders are staff or contractors of OHA or DHS. This includes those who must implement REALD in their data systems. **External** stakeholders are those external to OHA, such as culturally specific organizations.

Subpopulations or subgroups: Smaller groups within a broader category. For example, the Vietnamese subpopulation is a group within the broader Asian category. See also “granularity.”

Video relay service (VRS): VRS is a free, subscriber-based service for people who use sign language and have videophones, smart phones, or computers with video



communication capabilities.

For outgoing calls, the subscriber contacts the VRS interpreter. The VRS interpreter:

1. Places the call.
2. Serves as an intermediary between the subscriber and a person who uses a standard voice telephone.
3. Tells the voice telephone user what the subscriber is signing.
4. Signs to the subscriber what the telephone user is saying.

See <https://www.ada.gov/effective-comm.pdf> for more information.



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