

An Introduction to REALD data collection standards (Race, Ethnicity, Language and Disability)

October 9, 2020

While we wait to get started...

- We are recording this webinar.
- To access captioning, click on **captions – show subtitles**.
- For ASL interpreter access, you can “pin” the video on your screen to keep the interpreter view at all times.
- Private chat to Tom Cogswell if you are having technical challenges.
- If your name is not visible / clear, please rename yourself for clarity if possible.

Oregon
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Welcome and structure for today

- Introductions
 - Marjorie McGee, Ph.D., OHA Equity and Inclusion Division
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 - Belle Shepherd, MPH, OHA External Relations: BELLE.SHEPHERD@dhsoha.state.or.us
 - Tom Cogswell, OHA Transformation Center: THOMAS.COGSWELL@dhsoha.state.or.us
- Structure: Brief Q & A after each section (use Chatbox)
 - Today is REALD 101 – Introduction – What and Why
- Next week we have two webinars planned:
 - 10/14/2020: Provider implementation
 - 10/16/2020: How to ask the questions
- Please save questions about provider systems, workflow and how to ask the questions for these upcoming webinars.

Learning objectives

At the end of this training you will be able to:

1. Explain what REALD is, the purpose of REALD and how it came to be
2. Know how to access REALD resources on the OHA website – including templates and provider-specific resources
3. Understand the implications for providers reporting COVID-19 test results
4. Explain the connection between REALD, health equity and COVID-19.
5. Summarize how REALD can be used to identify and address health inequities.

REALD: What, why, history

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REALD – What? (Race, Ethnicity, and Language Disability)

- In 2013 [House Bill \(HB\) 2134](#) was proposed and passed
 - HB 2134 came from communities most impacted by health inequities
 - Asian Pacific American Network of Oregon (APANO)
 - Oregon Health Equity Alliance (OHEA)
- HB 2134 required ODHS and OHA to develop data collection standards in all programs that collect, record, or report demographic data.
- In 2014, these standards were codified in Oregon Administrative Rules [943-070-0000 through 943-070-0070](#) after an extensive rulemaking advisory process.
 - These rules were recently updated in 2020
 - Based upon local, state, and national standards and best practices

REALD – Why?

“The goal of eliminating disparities in health care in the United States **remains elusive...**”

- (Ulmer et al., 2009, p. 1; Institute of Medicine)

The lack of granularity in race/ethnicity can “...**mask important inequities in health and health care.**”

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

- Lack of standards = inconsistent and insufficient data collection
 - Can not assess how racism, disablism and lack of language access impact individual and community health
 - Makes services more expensive and less effective

REALD – Why?

- REALD:
 - Helps ensure access and equity in services, processes and outcomes
 - Provides consistency in data collection
- With REALD data, together we can:
 - Use information to improve client/patient/member services and reduce inequities
 - Identify inequities; determine what groups are most impacted
 - Address identified inequities through policy and legislative efforts
 - Reallocate resources and funds needed to effectively address these inequities
 - Design culturally appropriate and accessible interventions

Questions

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REALD Questions & Categories

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Core principles of REALD – Self-report

“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)

- Self-report is a core principle of REALD
- We do not believe there is just one right response in how people identify or answer the questions.
- Identities and responses to the REALD questions are salient to the person’s lived experiences.

For example...

Most patients with disabilities “... 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).

Core principles of REALD, continued

- **Active** (decline, unknown) responses
 - Vs. passive (system missing) responses
- **Combining race and ethnicity** improves data quality
 - For many who identify as Latino/a/x the distinction between race and ethnicity is not clear.
Combining race and ethnicity
 - Reduces use of “Other race”
 - Reduces missingness (Shin, 2015; Census Bureau’s Alternative Questionnaire Experiment)
- REALD is **fluid**.
 - Identities can change over time.
 - People can acquire limitations and/or have temporary limitations.
 - Answers to REALD questions are based on context and relationship with requestor
 - It is important to ask and re-ask the questions on a regular basis (annually for most settings) to capture changes over time and to improve data quality.

Three race/ethnicity questions

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

- Start with open-ended question before going to the 'labels'
- Can use to identify emerging populations and needs

Which of the following describes your racial or ethnic identity?

- 39 categories

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

Language questions

In what language do you want us to **communicate in person, on the phone, or virtually** with you?

In what language do you want us to **write** to you?

- If response to both questions above includes something other than “English”:

Do you need or want an **interpreter** for us to communicate with you?

If you need or want an interpreter, what **type of interpreter** is preferred?

- Spoken language interpreter, ASL interpreter, Deaf interpreter, Contact sign language (PSE), Other (please list)

How well do you speak English? (*English proficiency*)

- (very well, well, not well, not at all)

Defining disability....

- Challenges in defining disability....
 - Focus on disability as a demographic - population level – to identify and address inequities
 - Great diversity – by when the disability was acquired, and by type of disability
 - Stigmatization hinders “disability” pride – most do not identify as disabled
 - Need to reframe disability from medical model to “social model” (that includes impairment)
 - Exposure to abuse, violence
 - Exclusion (physical, communication, societal)
 - Pressure to conform (manage stigma)
 - Supports/resources needed to support equity in participation and daily living
 - Not dependent on eligibility definitions used to determine who gets what and how much

REALD disability questions use a functional limitation approach to help overcome these challenges in defining disability as a demographic.

Disability questions

All ages (hearing, vision):

- Are you deaf or have serious difficulty **hearing**?
- Are you blind or have serious difficulty **seeing**, even when wearing glasses?

Ages 5 and up (mobility, cognitive, learning, communicating, self-care):

- Do you have serious difficulty **walking or climbing stairs**?
- Because of a physical, mental, or emotional problem, do you have serious difficulty **remembering, concentrating**, or making decisions?
- Do you have serious difficulty **learning** how to do things most people your age can learn?
- Using your usual (customary) language, do you have serious difficulty **communicating** (for example understanding or being understood by others)?
- Do you have difficulty **bathing or dressing**?

Ages 15 and up (independent living, mental health):

- Because of a physical, mental, or emotional problem, do you have difficulty **doing errands alone** such as visiting a doctor's office or shopping?
- Do you have serious difficulty with the following: **mood, intense feelings, controlling your behavior, or experiencing delusions or hallucinations**?

Disability questions

- There is a follow-up question if a person answers yes.
 - “At what age did this condition begin?”
- This approach enables taking 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 disparities reflect inequities that go beyond genetics and personal choice” (Krahn et al., 2015, p. 199).
- The question acknowledges differences in potential social, educational and health inequities by asking when the disability or limitation was first acquired. It is important to know about these differences within groups so that we can identify and address disparities.

How to make REALD work for you...

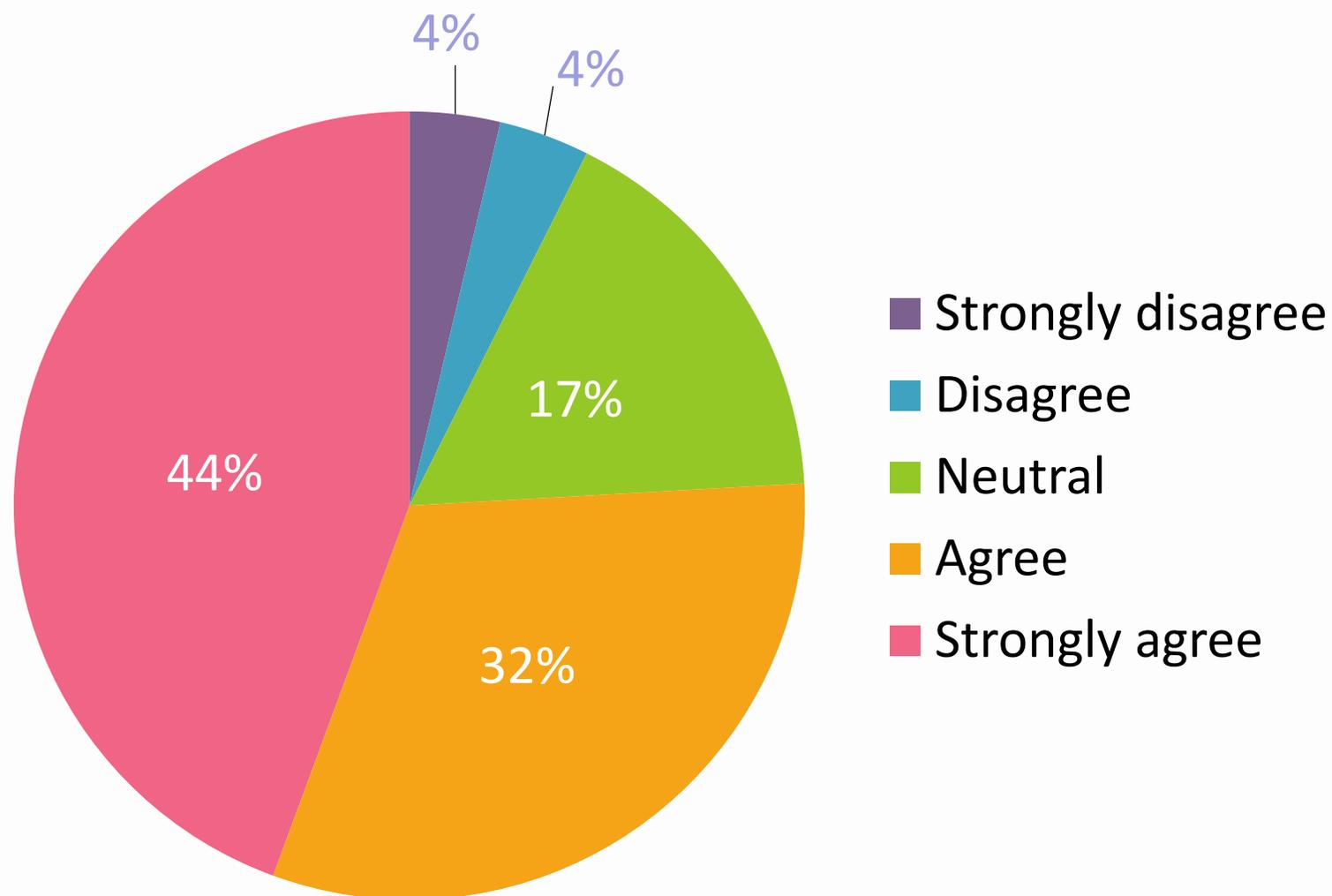
- At a **functional (individual) level**:
 - Enhances our SDOH learning about an individual
 - Understand lived experiences and impact on determinants of health
 - Counteract bias, stigma and assumptions
 - Enhances “patient/member/client-centered” approach
 - Provides space to invite the person to say more about what would be helpful or what they need to know
 - Tailors communications, services, treatment (culturally specific and accessible) for the person

How to make REALD work for you...

- At a **demographic (community) level**:
 - Identify inequities (between/within/intersectionally),
 - Address inequities through community action, policy and legislative efforts (for example, CHA/CHP),
 - Make the case for additional resources and funds needed to effectively address inequities,
 - Determine who are being served or surveyed,
 - 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.

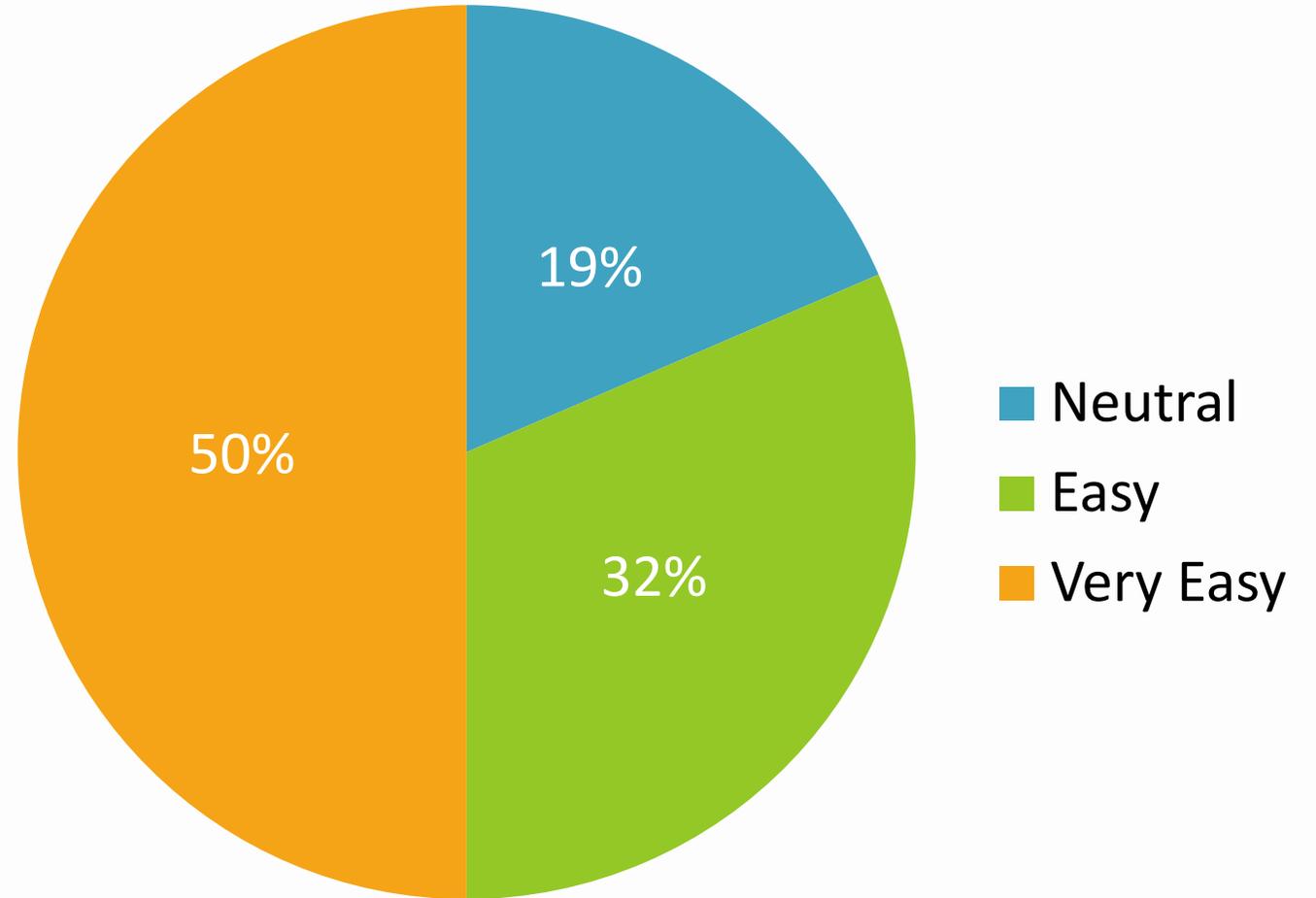
Good news!

Three quarters of people who answered the Webinar Survey (N=54) agreed that asking patients the REALD questions is important for health systems and providers to understand the diversity of folks they serve.

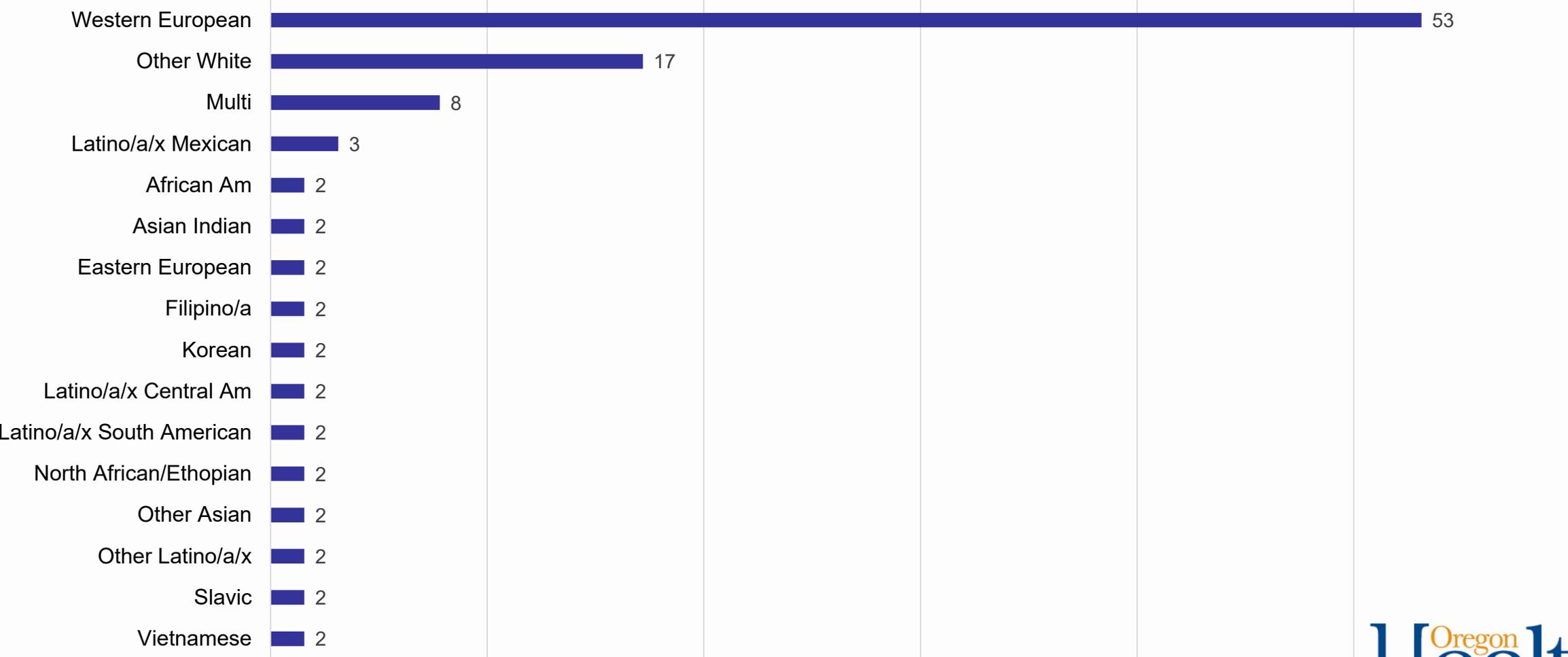


More good news!

Over 80% of survey respondents indicated that it was easy to answer the REALD demographic questions.



Primary race of webinar survey respondents (%)



Questions

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COVID-19 and REALD

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Who is most likely to be exposed to COVID-19?

- People of color and tribes – more likely to work in positions where not able to stay home
- People living in congregate care settings
- People who have limited mobility or who cannot avoid coming into close contact with others who may be infected, such as direct support providers and family members
- People who have trouble understanding information or practicing preventive measures, such as hand washing and social distancing
- People who may not be able to communicate symptoms of illness

Who is more likely to experience severe symptoms and die from COVID-19?

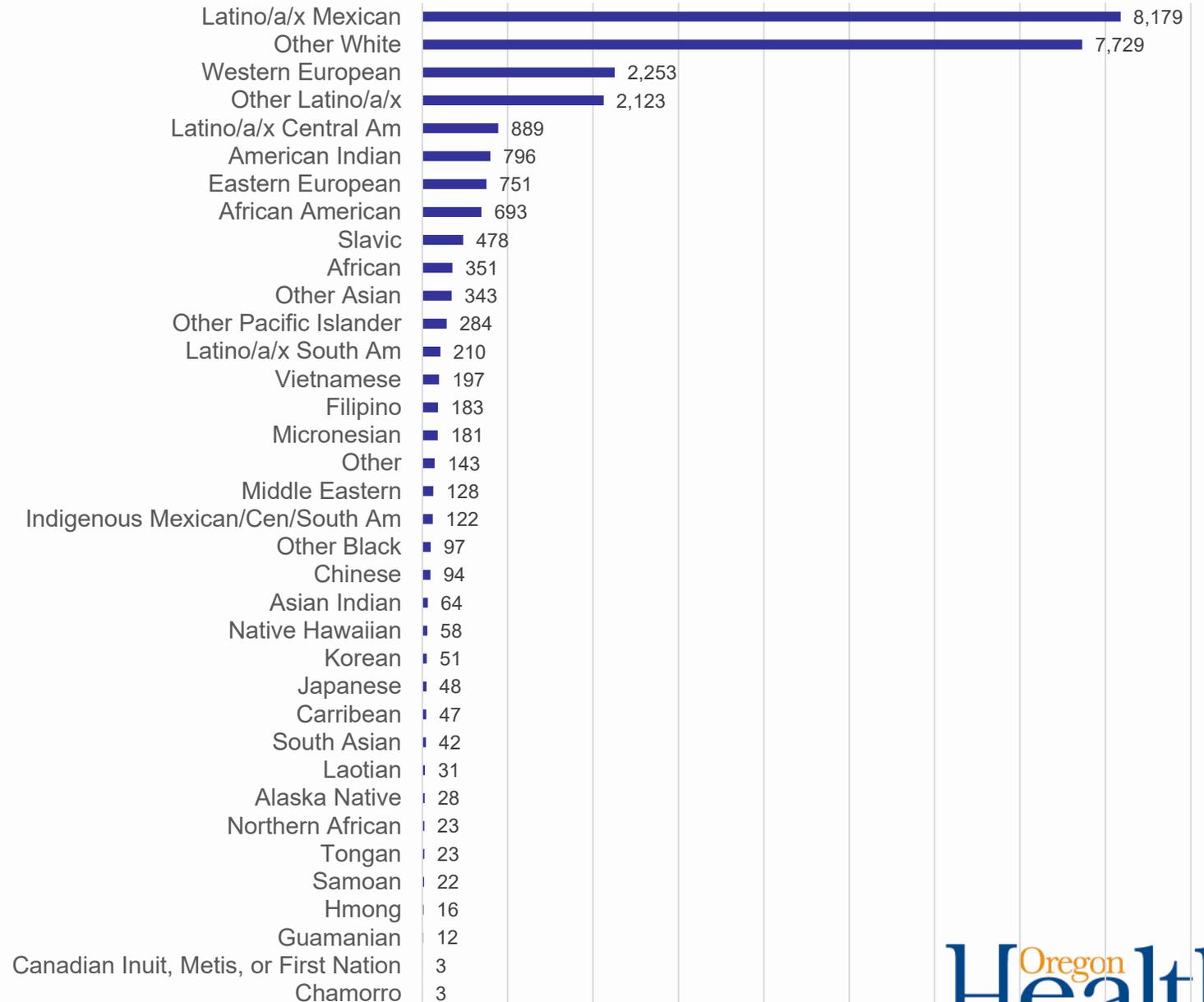
- People with underlying chronic conditions
 - Hypertension
 - Obesity
 - Metabolic disease
 - Cardiovascular diseases
 - Chronic lung diseases
- These underlying, chronic conditions not shared equally across all groups
 - COVID-19 magnifies persistent health inequities for people of color and people with disabilities.

Number of COVID-19 positive racial/ethnic identities

Note: These are tallies of identities, not individuals (N=26,605 COVID-positive cases)

Deeper dive resulted in adding these REALD categories:

- Communities of Myanmar
- Marshallese
- Communities of Micronesian Region
- Somali



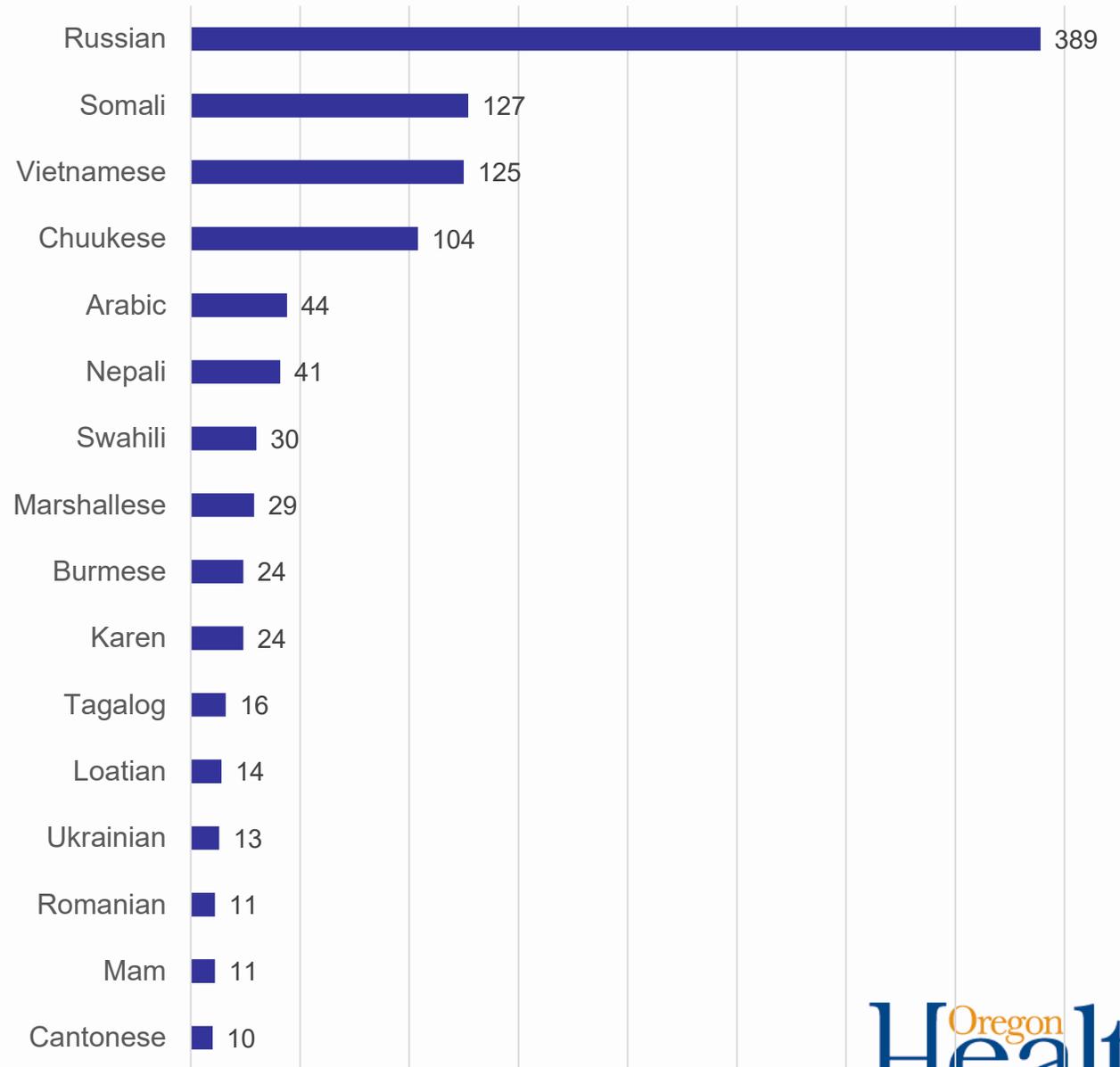
Preferred language (as of mid-September)

Notes:

Spanish was preferred for 7,190 individuals who tested positive for COVID-19.

This chart does not include other preferred language reported with counts under 10.

11,853 individuals with COVID-19 had **not** been asked questions about language preferences and needs.



What we know about COVID-19 and disability

- COVID-19 is over-represented among people with disabilities (PwD) (Chakraborty, 2020):
 - PwD of color
 - Below poverty
 - Age 5-17
 - Female
- Recent study with deaf individuals who use sign language suggests gaps in language access. Of those who went to the ED during the pandemic – 86% requested an interpreter
 - Of these, 33% did not get an interpreter, and
 - Of those who did get an interpreter, 40% did not understand the interpreter(N = 537, via Zoom; Kushalnager & Ammons 2020 CCPH Webinar: COVID-19 Research with Deaf People who use American Sign Language).

HB 4212 REALD data collection and reporting for providers

- House Bill 4212: COVID-19 legislation passed in June 2020
 - Requires OHA to establish rules related to REALD collection and reporting for COVID-19 encounters (OAR 333-018-0011)
- REALD data is required when reporting COVID-19 encounters that are reportable under Oregon Disease Reporting rules.
 - This includes COVID-19 tests (positive and negative), hospitalizations, deaths and MIS-C (Multisystem Inflammatory Syndrome in Children).
- Phase 1: Required starting October 1, 2020 for:
 - Hospitals, except for licensed psychiatric hospitals
 - Providers within a health system
 - Providers working in an FQHC
- Phase 2: Required no later than March 1, 2021 for:
 - Health care facilities
 - Health care providers working in or with individuals in a congregate setting.

HB 4212 REALD data collection and reporting for providers (continued)

- Visit the REALD provider page for HB 4212 implementation resources:
<https://www.oregon.gov/OHA/OEI/Pages/REALD-Providers.aspx>
 - FAQ: <https://www.oregon.gov/oha/OEI/REALD%20Documents/REALD-Data-Collection-Reporting-FAQ.pdf>
 - Implementation guide
 - Webinar series
 - Information related to collection and reporting
 - Extension request information
- For questions:
 - Contact Belle Shepherd at belle.shepherd@dhsoha.state.or.us

REALD resources

<https://www.oregon.gov/oha/OEI/Pages/REALD.aspx>

What is REALD?

REALD is an effort to increase and standardize Race, Ethnicity, Language, and Disability (REALD) data collection across the Oregon Department of Human Services (ODHS) and the Oregon Health Authority (OHA). REALD (sometimes referred to as REAL+D, as the original effort focused on race, ethnicity and language) was advanced through the passage of House Bill 2134 passed by the Oregon legislature in 2013.

HB 2134 required ODHS and OHA to develop a standard for collection of REALD data in conjunction with community stakeholders. The statutory authority for these rules is codified in the Oregon Revised Statutes (ORS) 413.042 and 413.161. In 2014 the Oregon Administrative Rules (OARs) detailing the data collection standards were completed (OARs 943-070-0000 thru 943-070-0070).

What's New:

October 1, 2020 Changes for Health Care Providers

Learn about requirements related to REALD data collection and reporting for COVID-19 encounters on the new REALD for Health Care Providers page.

[Visit REALD for Providers](#)

Provider Learning Series

Learn about REALD in OHA's fall learning series:

- Oct. 8, 2020: Introduction to REALD
- Oct. 14, 2020: Implementing new REALD data collection for Phase 1 providers (providers in hospitals, health systems, FQHCs)
- Oct. 18, 2020: Strategies for asking REALD questions
- Nov. 11, 2020: Using REALD data to advance health equity

Resources

[Checklists, Workflow Templates and Other Tools](#) +

[Oregon Administrative Rules and Policies](#) +

[Other Resources](#) +

[Reports](#) +

Implementation Guide

[Read the Guide](#)



REALD Templates (paper forms)

[View All Templates](#)

Includes general information and links to all five versions in 20 languages

Quick Links

Service-based settings (such as health care, contact tracing, social services):

- English – all ages
- Spanish – all ages
- All languages – all ages

Non-service-based settings (such as surveys):

- English – all ages
- Spanish – all ages
- All languages – all ages

Future learning sessions

- **Implementing new REALD data collection for providers.** 10/14, 2-3:30 p.m.
 - Registration link: <https://attendee.gotowebinar.com/register/780285329347906062>
- **Strategies for Asking REALD questions.** 10/16, noon-1 p.m.
 - Registration: <https://www.eventbrite.com/e/strategies-for-asking-read-questions-tickets-120069439927>
- **Using REALD Data to Advance Health Equity.** 11/20, noon-1 p.m.
 - Registration: <https://www.eventbrite.com/e/using-read-data-to-advance-health-equity-tickets-120070858169>

Whom to contact

- For questions on implementing REALD, use of REALD tools and data reporting:
 - Contact Marjorie McGee at marjorie.g.mcgee@dhsosha.state.or.us
- For questions on HB 4212 Collection and Reporting of REALD for COVID-19 encounters:
 - Contact Belle Shepherd at belle.shepherd@dhsosha.state.or.us
- For questions about the electronic data exchange for ELR or eCR for reporting COVID-19:
 - Email to ELR.project@dhsosha.state.or.us mailbox.

Questions

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