Oregon's Race, Ethnicity, Language and Disability Summary Novel Coronavirus (COVID-19)



COVID-19 Race, Ethnicity, Language and Disability (REALD) Report

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Introduction

House Bill 4212 (2020) directed the Oregon Health Authority (OHA) to adopt rules requiring health care providers to collect and report to OHA data on Race, Ethnicity, Language and Disability (REALD) during all health care encounters for reportable COVID-19 conditions: cases, positive and negative tests, hospitalizations, deaths and Multi-inflammatory Syndrome in Children (MIS-C).

The goal of this report is to demonstrate the importance and benefits of REALD data, namely information about the diversity of people living in Oregon who have a reported case of COVID-19 or have had a reported COVID-19 health care encounter. REALD data collection provides more information about self-identified racial and ethnic identity, preferred spoken and written languages, interpreter needs, English proficiency and disability. As the value of REALD depends on data quality and completeness, the first part of this report will outline some of the challenges of REALD implementation. The second part of this report will highlight the effects of COVID-19 in Oregon using REALD. Finally, this report proposes recommendations for improvement and further investigation.

What is REALD and Why is it Important?

REALD is a standardized way to collect granular race, ethnicity, language, and disability data in Oregon. Collecting REALD is important because it identifies health inequities among populations that we work with or serve. These data help us measure the magnitude of disproportionate effects, identify the populations experiencing these inequities, and guide the development of culturally specific and accessible services. In the COVID-19 pandemic REALD collection is necessary to better understand the impact of the pandemic and how health inequities persist and create greater vulnerability for disproportionately impacted communities especially tribal communities, communities of color, immigrant and refugee communities and people with disabilities. For more information about REALD please visit the OHA REALD website.

REALD Data Sources

Cases

Oregonians who test positive for COVID-19 or who are presumptive cases of COVID-19 are interviewed by their local or tribal public health authority. Case investigators ask cases where they may have been before they got COVID-19, any close contacts they may have had while infectious, and if any wraparound services are needed. As part of the interview, people are also asked for their demographic information, including their racial or ethnic identity, preferred

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language, and disability. Answers are recorded in Oregon's COVID-19 case investigation database. REALD information collected for COVID-19 cases by public health case investigators is labeled in this report as **cases**.

Encounters

As of October 1st, 2020, hospitals¹ and health care providers within a health system or working in a federally qualified health center (i.e., Phase I providers) are required to collect REALD data on all patient COVID-19 encounters, and report that information to OHA for reportable COVID-19 conditions. These data are required to be submitted electronically either by a secured file transfer protocol (SFTP) per OHA specifications or through our secure, web-based confidential reporting system, Oregon COVID Reporting Portal (OCRP). REALD information collected by providers during health care encounters and reported to OHA for reportable COVID-19 conditions is labeled in this report as **encounters**. Encounters include some cases of COVID-19 but represent a broader range of COVID-19 conditions (i.e., positive and negative tests, hospitalizations, deaths and Multi-inflammatory Syndrome in Children (MIS-C)) and span a shorter time period in this report: case investigation data are from February through December 2020 while COVID-19 health care encounter data are from October, when House Bill 4212 was implemented, through December 2020.

OHA received 53,141 REALD reports on COVID-19 encounters from 437 unique hospital and health care provider reporters. The organization type is known for 55% of COVID-19 encounter REALD reports.

Phase II providers, which include health care facilities and health care providers working in or with individuals in a congregate setting, are not required to begin collecting or submitting REALD data until March 1st, 2021. A significant number of Phase II providers have already adopted REALD and have been submitting disaggregated REALD data, however. This is due, at least in part, to OHA funded community-based testing events with long-term care facilities, local public health authorities and EMS which required REALD data collection.

Among identified reporters, the most REALD reports came from health care systems followed by long-term care facilities and private practice or clinical settings (Table 1). 'Other/Unclassified' organizations include senders that either do not fall within our specified categories or whose

¹ Except for licensed psychiatric hospitals.

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organizations have not been identified. This is primarily due to the optional and open text field nature of the Oregon COVID-19 Reporting Portal (OCRP).

Table 1. Number and percent of COVID-19 encounter REALD reports submitted by organization type

Organization Type*	Number of Reports	% of Reports
Unknown, Provider Organization not reported	23,930	45.0%
Healthcare System	13,429	25.3%
Long-term Care Facility	4,691	8.8%
Private Practice/Clinic	4,119	7.8%
Hospital	3,021	5.7%
Public Health	1,020	1.9%
Federally qualified healthcare center (FQHC)	920	1.7%
Correctional Facility	654	1.2%
Other/Unclassified	540	1.0%
Student Health	407	0.8%
Tribal Health	207	0.4%
Dialysis Center	75	0.1%
EMS/Fire	71	0.1%
Psychiatric Facility	51	0.1%
Laboratory	5	0.0%
Pharmacy	1	0.0%
Grand Total	53,141	100.0%

^{*}Phase I organization types are bolded

REALD Data Methods

To capture the diversity of racial and ethnic identities, the REALD questionnaire first asks people an open question of how they identify in terms of their race, ethnicity, tribal affiliation, country of origin, or ancestry. This is intended to allow the person to identify in any way they want before selecting one or more categories from a nested list of racial and ethnic groups. Open text responses were used to impute disaggregated racial or ethnic identities (e.g. Vietnamese, Marshallese, Chinese) if no category was selected. Aggregate racial or ethnic identity was imputed using open text responses and labeled with "sansREALD" (i.e., string answer REALD) if no disaggregated racial or ethnic category was selected. The third question about race and

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ethnicity pertains to a person's primary racial or ethnic identity. If primary race or ethnicity information was not provided directly by the person, primary race or ethnicity was imputed using the "most identify/rarest" group method (Mays, Ponce, Washington, & Cochran, 2003) for those who selected two or more racial or ethnic identities.

The open response of the preferred language field captures a lot of diversity and is also prone to misspellings or use of related terms. Upon review, alternate spellings were grouped (e.g., Palau and Palauan). Languages determined to be closely related were explicitly grouped (e.g., Cambodian, Khmer). General responses (e.g., Micronesian) were explicitly grouped with related languages in the same family (e.g., Marshallese, Chuukese, Trukese, Carolinian, Pohnpeian). If multiple languages were identified, preferred language was determined using the rarest group method. For example, those who identify both Polish and Dutch as the language used at home were grouped with a preferred language of Dutch because it was less frequently reported.

Interpreter needs were assessed for those who indicated a preferred spoken or written language other than English. English proficiency was also assessed for people who indicated they speak a language other than English at home (excluding sign language). Respondents selected from four categorical variables: "very well", "well", "not well", "not at all".

The disability questions are based on functional limitations, which avoids the challenges of collecting disability by identities or by diagnoses. This is the approach used to understand at a population level the number and percent of people with disabilities. There are four major domains of disability (i.e., vision, hearing, mobility and cognitive) represented in six disability questions. Three additional disability questions serve as proxies for severity (i.e., difficulty doing errands alone, dressing or bathing, communicating). A follow up question asks at what age the condition began for each disability question. Because there is great diversity in lived experiences affecting health outcomes among people with disabilities – both by type of disability and by age acquired – this report synthesizes disability data in two ways: 1) stratifying by those who identified as having one disability, having independent living or self-care limitations, or having two or more disabilities, and 2) considering the age range in which the condition began (or current age if the age acquired information was missing) in combination with type of disability.

REALD Data Limitations

Public health endeavors to interview every case of COVID-19, but not every person is reached. Under surge conditions, where response activities are modified to ensure resources are focused on serving the most vulnerable Oregonians, REALD remain high-priority interview questions.

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However, the number of outreach attempts may be limited which can lead to a lower response rate.

In October 2020, the REALD standards were updated to include five new racial or ethnic categories, to expand the language questions, and to add three new disability questions. With the addition of updates come challenges with inconsistent data collection processes. Training is offered to local and tribal public health authorities and case investigators on best practices for collecting REALD information.

Some missing or optional fields in the REALD data collection tools used for encounters limit our ability to interpret these data. The original specifications for transmitting REALD encounter data to OHA by comma separated values (CSV) did not include encounter type, thus it is difficult to delineate why patient information was collected and sent. As of December 18^{th,} 2020, the CSV specifications have been updated to require encounter type. Additionally, nearly half (45%) of provider organization data, an optional field in OCRP, are missing from COVID-19 encounter REALD reports (Table 1); this limits our ability to fully understand who reports REALD data. Age at which disability was acquired is currently not required in OCRP, which contributes to incomplete data.

Duplicate data is also an issue affecting both COVID-19 case and encounter data. Even with deduplication efforts duplicate data remain and we are working on refining our methodology. Currently, data cleaning methods include using various personal identifiers (e.g., record ID number, name, date of birth or age, ZIP code) to deduplicate records. Duplicative records may occur for a multitude of reasons including case investigators creating a second record for a person in the case investigation database, or different providers sending information for the same patient.

Data Completeness

Racial or ethnic identity, language and disability fields were analyzed for completeness. REALD questions about primary race or ethnicity category were most complete (82.9% of cases, 62.9% of encounters; Table 2), followed by preferred language (60% of cases, 85.1% of encounters). Data are less complete for English proficiency, interpreter need and disability. Information on English proficiency is only available for 49.8% of cases and 36.6% of encounters who preferred a non-English language. Likewise, information on interpreter need is only known for 13% of cases and 55.4% of encounters. Completeness of disability information is also low (34.8% of cases, 38.8% of encounters).

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Table 2. Completeness of REALD variables

REALD Variable	Complete n (%)	Unknown n (%)	Declined n (%)	Missing n (%)	Total
Primary race or ethnicity*					
Cases	93,838	1,033	1,090	17,196	113,157
	(82.9%)	(0.9%)	(1%)	(15.2%)	
Encounters	37,814	9,275	4,295	8,727	60,111
Elicounters	(62.9%)	(15.4%)	(7.1%)	(14.5%)	00,111
Preferred language					
Cases	67,894	0	135	45,128	113,157
Cases	(60%)	(0%)	(0.1%)	(39.9%)	113,137
Encounters	51,184	373	681	7,873	60,111
Encounters	(85.1%)	(0.6%)	(1.1%)	(13.1%)	00,111
English proficiency†					
Casas	9,552	679	34	8,926	10 101
Cases	(49.8%)	(3.5%)	(0.2%)	(46.5%)	19,191
Encountors	1,204	1,099	133	857	2 202
Encounters	(36.6%)	(33.4%)	(4%)	(26%)	3,293
Interpreter need†					
Canad	2,497	4,308	0	12,386	19,191
Cases	(13%)	(22.5%)	(0%)	(64.5%)	
Francischer	1,825	1,825 161 0 1,307			
Encounters	(55.4%)	(4.9%)	(0%)	(39.7%)	3,293
Disability					
Cases	39,419	975	394	72,369	112 157
	(34.8%)	(0.9%)	(0.3%)	(64%)	113,157
Encountors	23,312	12,430‡	4,143	20,226	60 111
Encounters	(38.8%)	(20.7%)	(6.9%)	(33.6%)	60,111

^{*}Primary race or ethnicity was aggregated at the "most identify/rarest" group method.

[†]English proficiency and interpreter need are only assessed for people who prefer a non-English language.

[‡]Includes responses of "Not Understand".

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Statewide REALD Data Analysis: Racial and Ethnic identity

Race and ethnicity data are available for 82.9% of COVID-19 cases and 62.9% of reported COVID-19 encounters. Among people who provided information on their self-identified racial or ethnic identity, most people identified as white followed by Hispanic or Latino/a/x (Figure 1).

Less than 5% of COVID-19 cases identified as each of the following racial or ethnic categories: Asian, Black and African American, American Indian and Alaska Native, or Native Hawaiian and Pacific Islander. 1% of COVID-19 cases identified as "Other race", more than 1 race, or Middle Eastern and North African.

Less than 5% of people with a reported COVID-19 encounter identified as each of the following racial or ethnic categories: Asian, Black and African American, American Indian and Alaska Native, or "Other race". Less than 2% of people with COVID-19 encounters identified as Native Hawaiian and Pacific Islander, more than 1 race or Middle Eastern/North African.

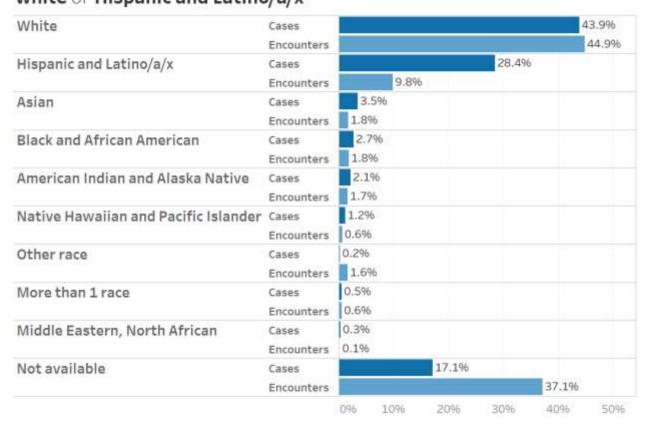
More cases than encounters identify as Hispanic and Latino/a/x (28.4% of cases, 9.8% of encounters). One possible explanation would be if the Hispanic and Latino/a/x community has insufficient access to testing and this warrants further investigation.

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Figure 1. Self-reported REALD racial or ethnic identity of COVID-19 cases and encounters

Most Oregon COVID-19 cases and encounters in 2020 identified as white or Hispanic and Latino/a/x



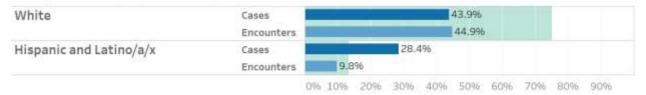
Population information is not available for each of the REALD racial or ethnic categories, and the data that are available collect separate race and ethnicity data rather than the combined categories in REALD. Comparing the REALD responses for racial or ethnic identity groups to the proportion of the population in available data sources helps identify health inequities (Figure 2). People who identify as Hispanic and Latino/a/x, Black and African American, American Indian and Alaska Native, and Native Hawaiian and Pacific Islander have all been disproportionately affected by COVID-19.

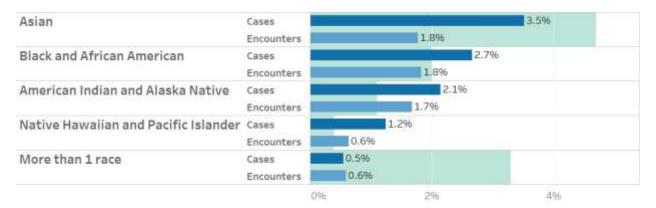
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Figure 2. REALD racial or ethnic identity of COVID-19 cases and encounters compared to population proportion*

Racial or ethnic identity of Oregon COVID-19 cases and encounters in 2020 compared to population proportion





^{*}Population estimates from the 2019 Census Bureau. White (not Hispanic or Latino), 75.1%; Hispanic (all races), 13.4%; Asian (not Hispanic or Latino), 4.7%; More than 1 race (not Hispanic or Latino), 3.3%; Black or African American (not Hispanic or Latino), 2.0%; American Indian or Alaska Native (not Hispanic or Latino), 1.1%; Native Hawaiian and Other Pacific Islander (not Hispanic or Latino), 0.4%.

Note that the scale is reset after the top two categories to better visualize smaller proportions

Racial or ethnic identity, expanded

Responses to the expanded racial and ethnic categories in REALD data can provide additional insight within demographic groups and help customize public health interventions to the communities most affected. REALD includes 38 discrete racial or ethnic categories that a person can select from, as well as 'Don't' Know' and 'Don't want to answer' (Figure 3). Categories labeled as 'sansREALD' (i.e., string answer REALD) describe responses in open text or aggregate race groups only. Individuals who selected multiple categories as their primary racial or ethnic identity were assigned to a group using the "most identify/rarest" group methodology for analysis

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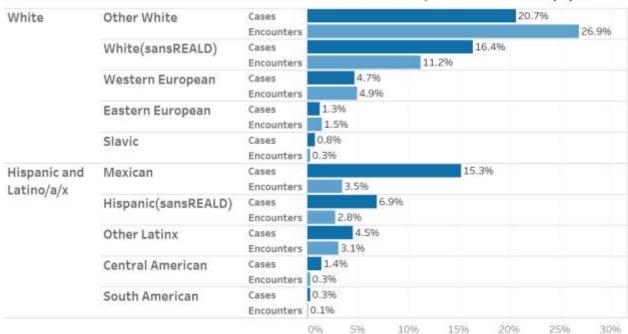
purposes. Racial or ethnic identities of either Other White, White, or Western European made up 41.8% of the COVID-19 case responses and 43% of COVID-19 encounter responses. Mexican, Hispanic, and Other Latinx were also amongst the top categories statewide (26.7% of cases, 9.4% of COVID-19 encounters).

We noted previously the divergence between the proportion of cases and encounters who identify as Hispanic and Latino/a/x. From these expanded categories, we can see a marked difference among those who further identify as Mexican (15.3% of cases, 3.5% of encounters; Figure 3). These data can be used to inform health education outreach and testing events to better meet the need of this community.

Figure 3. Expanded REALD racial or ethnic categories for COVID-19 cases and encounters

REALD provides further detail on racial or ethnic identity:



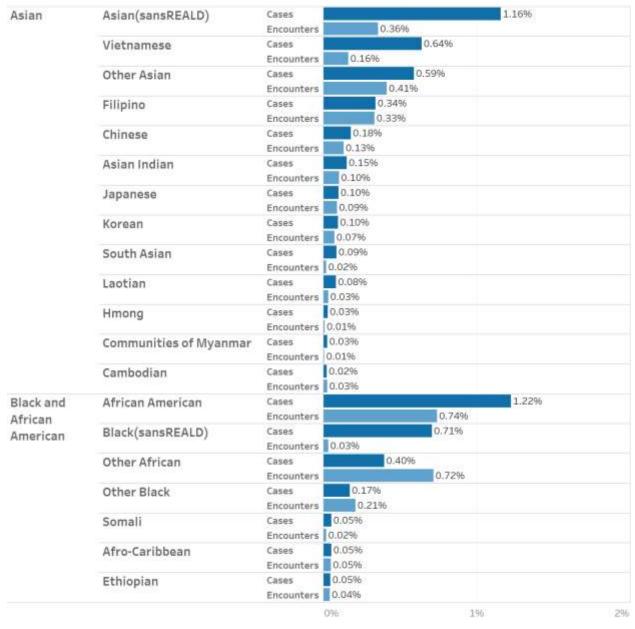


The remaining expanded racial or ethnic categories are continued below. Note that the scale is reset from the top two aggregate categories to better see in-group frequencies.

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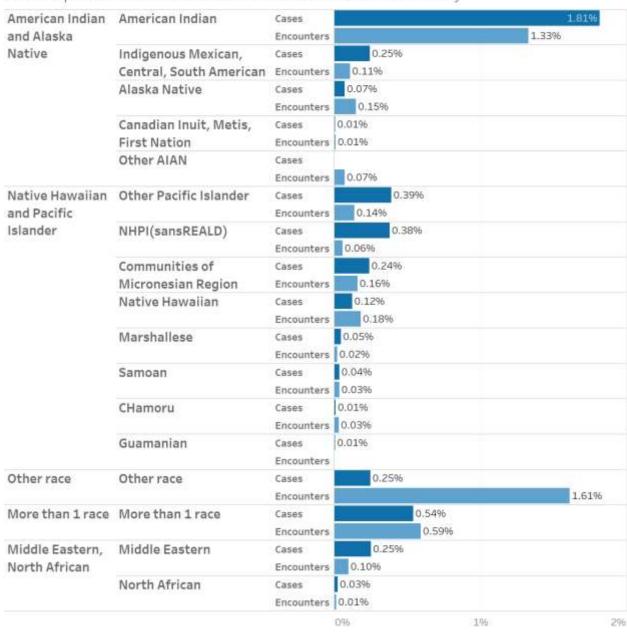
REALD provides further detail on racial or ethnic identity



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REALD provides further detail on racial or ethnic identity



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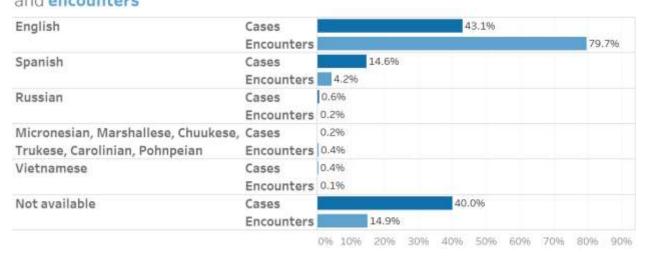


Statewide REALD Data Analysis: Language

REALD allows for open text specification for preferred spoken or written language. A preferred language is not documented for 40% of COVID-19 cases and 14.9% of COVID-19 encounters. Of all language information received, most people preferred either English (43.1% of cases, 79.7% of encounters) or Spanish (14.6% of cases, 4.2% of encounters). Russian, a family of Micronesian languages (i.e., Marshallese, Chuukese, Trukese, Carolinian, Pohnpeian), and Vietnamese were next most frequent preferred languages (Figure 4).

Figure 4. Top preferred languages for COVID-19 cases and encounters

English was the most common preferred language for both COVID-19 cases and encounters

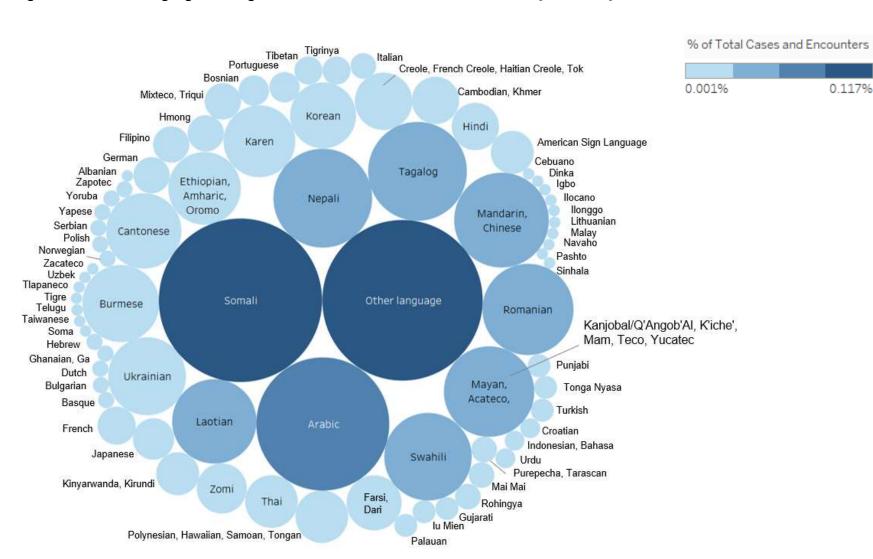


More than 100 languages are represented in the preferred language responses however, which reflects the diversity of Oregonians affected by COVID-19 and the challenge local public health authorities face to effectively interview people who prefer a language other than English (Figure 5; Appendix A). Responses of 'Other language' may reflect limitations in the ability of various data collection tools to capture all preferred languages. Interpreter need and English proficiency were assessed for people who preferred a non-English language (excluding sign language). These data should be interpreted with caution as data on interpreter need are not available for most cases and almost half of encounters who preferred a non-English language. Where interpreter information is available, spoken language interpretation is the most frequently requested type (Figure 6). Likewise, information on English proficiency is not available for more than half of cases and encounters who preferred a non-English language. (Figure 7).

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Figure 5. Preferred languages among COVID-19 cases and encounters combined [continued]



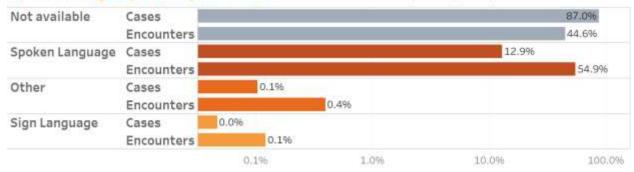
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Figure 6. Interpreter need among COVID-19 cases and encounters who prefer a language other than English

Among people who preferred a non-English language, information on interpreter need is **not available** for **87% of cases** and **45% of encounters**.

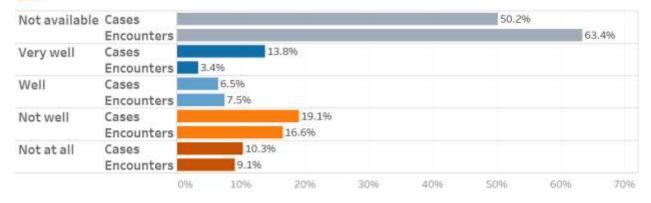
Spoken language interpretation was the most frequenty requested.



Note a logarithmic scale is used to better visualize smaller proportions; each tick mark is a ten-fold increase.

Figure 7. English proficiency among COVID-19 cases and encounters who prefer a language other than English

Among people who preferred a non-English language, 29% of cases and 26% of encounters either did not speak English well or did not speak English at all.



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Statewide REALD Data Analysis: Disability

Disability information was not available for 65.2% of COVID-19 cases and 61.2% of COVID-19 encounters. 31.1% of cases and 31.6% of encounters reported having no disabilities. 3.7% of cases and 7.2% of encounters identified a disability. Of all disability types, independent living and self-care limitations were most frequently reported at 1.3% of cases and 3.5% of encounters (Figure 8), which may affect the ability of COVID-19 cases to successfully isolate while infectious. It should also be noted that independent living and self-care limitations are often a proxy for the severity of disabilities; people who report independent living and self-care limitations often have another limitation.

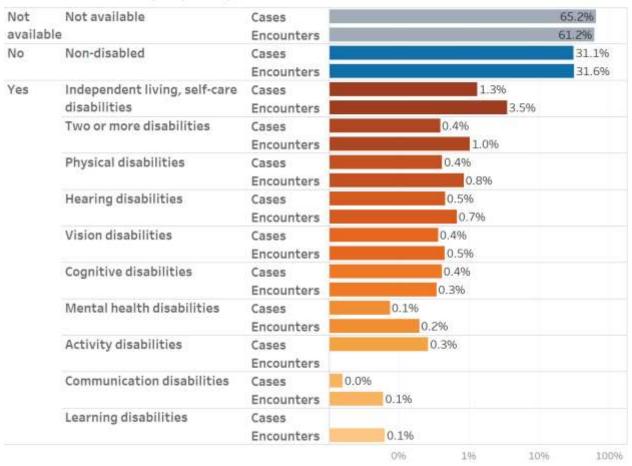
When we look at disability by age at which the condition began, the most frequently reported functional limitations were acquired at age 50 or more (Figure 9). Of note, the proportion of health encounters who report a disability acquired before age 19 (split into two categories by type) or at age 50 or more is two to three times more than the proportion of cases (Figure 9). This may be reflective of coordinated testing efforts in congregate living settings.

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Figure 8. Disability of COVID-19 cases and encounters by type

Disability information is **not available** for **65% of cases** and **61% of encounters**. Most people reported **no functional limitations**.



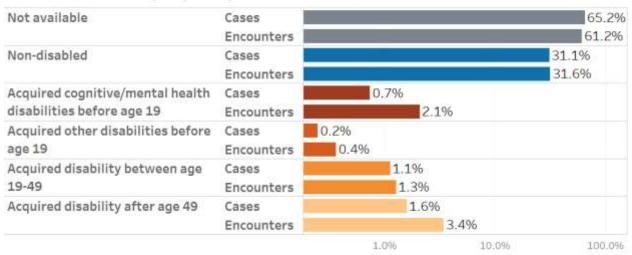
Note a logarithmic scale is used to better visualize smaller proportions; each tick mark is a ten-fold increase.

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Figure 9. Disability of COVID-19 cases and encounters by age acquired

Disability information is **not available** for **65% of cases** and **61% of encounters**. Most people reported **no functional limitations**.



Note a logarithmic scale is used to better visualize smaller proportions; each tick mark is a ten-fold increase.

Discussion

House Bill 4212 requires health care providers to collect race, ethnicity, language and disability data for all COVID-19 encounters in a new or different way conforming to REALD standards. While asking REALD questions may only take five minutes for an experienced interviewer, there is an art to asking these questions in an effective and trauma informed way. In addition to the stress and anxiety induced by the COVID-19 pandemic, interactions with the medical or governmental personnel may be triggering due to previous adverse experiences or the current and historical oppression experienced by many communities.

Interpretation of English proficiency, interpreter need and disability data is limited due to the degree of missing data. There are many contributing factors to the missingness of data, including the data collection tool used (i.e., paper or electronic forms) which affects the steps required between interview and analysis. While paper forms can be easier to implement, entering data from paper forms takes time and can delay analysis. There can be disconnects between asking, recording, and entering responses; standardization can be improved with additional training. The existing electronic infrastructure works and can be improved to support the data collection

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process with additional validation of data across fields and features to support the multiple freetext fields, reduce the amount of data cleaning required, and facilitate analysis.

Due to the role that REALD data play in better informing our understanding of the impact of health inequities particularly in a pandemic, it will be important to continue to work to overcome the barriers to REALD data collection.

Conclusions

Obtaining REALD data is a vital approach to collecting demographic information. Granular data allow us to understand the intricacies of health inequities and better comprehend how identity intersectionality manifest into differing health outcomes. REALD allows us to understand which populations in Oregon have experienced the greatest burden of COVID-19 infections and which populations in Oregon are able to access health care for COVID-19 specific care. These data will be used to identify populations where health inequities are prevalent and affect the ability to access necessary COVID-19 testing and education. In this report we have highlighted that:

- More cases than encounters identified as Hispanic and Latino/a/x, possibly indicating insufficient access to testing,
- Cases and encounters preferred more than 100 non-English languages, posing a potential challenge for effectively interviewing people in their own language, and
- More encounters than cases report a disability acquired either before the age of 19 or at age 50+, which may reflect coordinated testing efforts in congregate living settings.

The REALD initiative is bigger than any one program. The state of Oregon may want to consider developing centralized data systems to receive REALD data consistently across all agencies. OHA may also want to consider additional data collection tools, including a HIPAA compliant electronic REALD survey to minimize exposure and reduce frustration trying to communicate while using masks.

Although these data allow us to delineate populations within Oregon who have been infected with or have had health care encounters for COVID-19, REALD data at the county level will further help identify health inequities. Future iterations of this report will examine REALD data at the county level; include race, ethnicity and language information from other data sources for a more complete picture; and compare findings to adjunct data sources.

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Appendix A. Additional preferred languages among COVID-19 cases and encounters combined

Preferred Language	% of Cases and Encounters
Somali	0.117%
Other language	0.113%
Arabic	0.077%
Nepali	0.043%
Tagalog	0.043%
Mandarin, Chinese	0.039%
Romanian	0.036%
Mayan, Acateco, Kanjobal/Q'Angob'Al, K'iche', Mam, Teco, Yucatec	0.036%
Swahili	0.033%
Laotian	0.031%
Ukrainian	0.027%
Burmese	0.026%
Cantonese	0.025%
Ethiopian, Amharic, Oromo	0.023%
Karen	0.023%
Korean	0.019%
Creole, French Creole, Haitian Creole, Tok	0.014%
Farsi, Dari	0.013%
Polynesian, Hawaiian, Samoan, Tongan	0.012%
Thai	0.012%
Zomi	0.011%
Cambodian, Khmer	0.010%
Hindi	0.010%
American Sign Language	0.008%
Kinyarwanda, Kirundi	0.008%
Japanese	0.008%
French	0.006%
Filipino	0.006%
German	0.006%
Hmong	0.006%

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Preferred Language	% of Cases and Encounters
Mixteco, Triqui	0.006%
Bosnian	0.004%
Portuguese	0.004%
Tigrinya	0.003%
Tibetan	0.003%
Italian	0.003%
Mai Mai	0.003%
Purepecha, Tarascan	0.003%
Rohingya	0.003%
lu Mien	0.002%
Palauan	0.002%
Punjabi	0.002%
Tonga Nyasa	0.002%
Turkish	0.002%
Gujarati	0.002%
Indonesian, Bahasa	0.002%
Urdu	0.002%
Croatian	0.002%
Basque	0.001%
Bulgarian	0.001%
Dutch	0.001%
Ghanaian, Ga	0.001%
Hebrew	0.001%
Norwegian	0.001%
Polish	0.001%
Serbian	0.001%
Yapese	0.001%
Yoruba	0.001%
Zapotec	0.001%
Albanian	0.001%
Cebuano	0.001%
Dinka	0.001%

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Preferred Language	% of Cases and Encounters
Igbo	0.001%
Ilocano	0.001%
Ilonggo	0.001%
Lithuanian	0.001%
Malay	0.001%
Navaho	0.001%
Pashto	0.001%
Sinhala	0.001%
Soma	0.001%
Taiwanese	0.001%
Telugu	0.001%
Tigre	0.001%
Tlapaneco	0.001%
Uzbek	0.001%
Zacateco	0.001%