

Oregon's Effort to Improve Data Collection for All People

Introduction

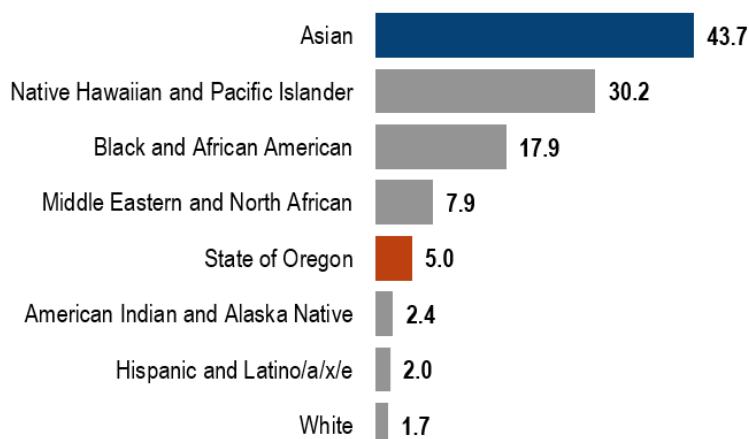
The purpose of this summary is to demonstrate how collecting detailed race and ethnicity data can be used to better identify differences in rates of communicable disease, like hepatitis B, among racial and ethnic groups. Collecting high-quality race and ethnicity data is an essential part of the Oregon Health Authority's ([OHA](#)) [strategic plan to eliminate health inequities](#). While race and ethnicity data have been collected at all levels of government for decades, OHA's commitment to collecting these data at greater levels of granularity or detail allows those using public health data to better identify disease burden among different populations. This can help in both determining the underlying causes of disease which arise from the social and structural determinants of health and in directing public health resources to mitigate their impacts on individuals.

This summary examines chronic hepatitis B, a well-known problem among communities who come to the United States from Asia. The prevalence of hepatitis B among Asian populations is well-documented in public health research, indicating a long-standing need to explore disparities and opportunities for prevention. Current prevention includes a vaccine for hepatitis B that has been available since 1982. Pregnant women are routinely screened for hepatitis B, contacts are offered vaccination, and newborns are vaccinated, given immunoglobulin to prevent infection, and followed by local public health to ensure completion of care and immunity to infection.*

In Oregon and nationally, detailed demographic data on Asian subgroups have not been collected until recently. The detailed

Figure 1: The highest rate of reported chronic hepatitis B infection is among people who identify as **Asian**.

Average annual rate of reported chronic hepatitis B infection per 100,000 people in Oregon, 2021–2024.



Data source: Orpheus, 1/21/2025; American Community Survey (ACS) 5-year Public Use Microdata Sample (PUMS) population estimates 2017–2021

data in this summary show distinct differences in hepatitis B prevalence among Asian subgroups. This has implications for providing culturally-specific education and disease prevention for communities in Oregon.

Evolving standards for race and ethnicity data collection

Standards for collecting race and ethnicity data at the federal level are set by the Office of Management and Budget (OMB) in [Statistical Policy Directive No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity \(SPD 15\)](#). In Oregon, race and ethnicity data-collection standards are more expansive than those in the OMB

guidelines and are responsive to local community advocacy for culturally specific data. The [2024 REALD & SOGI standards](#)[†] are the current guidelines for race and ethnicity data collection and include open-ended, multi-select, and write-in response options to improve specificity. By including these options, OHA has the opportunity to collect more robust, detailed data.

Increasing the level of detail allows members of the community to be better reflected in the data by having categories that more closely align with how they identify. Increased granularity also allows us to assess how smaller groups within broad categories experience outcomes across reportable

*[Oregon Perinatal hepatitis B prevention program](#) (PHBPP)

[†]Oregon Administrative Rules (OAR), [OHA Equity & Inclusion Division chapter 950, division 30 REALD and SOGI Demographic Data Collection Standards](#)

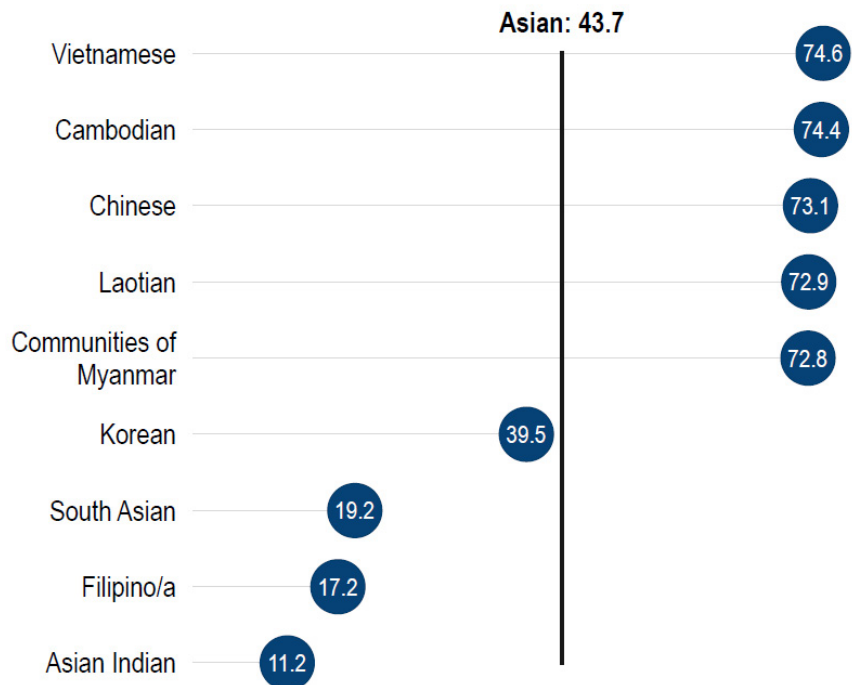
communicable diseases and what may be driving these outcomes. To illustrate this point, we have data on chronic hepatitis B among those who identify as Asian. Rates of chronic hepatitis B are higher among those who identify as Asian in Oregon (Figure 1), nationally and globally.^{1,2} Globally, those who have origins in Asia have higher rates of hepatitis B than those who have origins elsewhere, though rates of hepatitis B have been found to vary across time and place given socioeconomic conditions and healthcare infrastructure. Chen et al. found that, while both hepatitis B and C appear to be declining in Asia over the last 30 years, the disease burden is higher in Afghanistan, Cambodia, Mongolia, and Pakistan than other Asian countries.² Xie et al. found that rates of hepatitis B are higher in Southeast Asia and West Asia than in East and South Asia.³ Some of the driving factors are: hepatitis care not being a part of primary healthcare, high treatment costs, lack of education about the disease, and inaccessibility of screenings to identify those who are infected.⁴

In the United States, those who are foreign-born often make up a significant percentage of those with hepatitis B, with rates often being the highest among those who come to the U.S. from Asia.^{5,6} Once in the U.S., many Asian individuals with hepatitis B lack access to screenings, vaccination, education about disease prevention, culturally competent care, and health care in their preferred language.⁷ Children of Asian people who come to the U.S. are also more likely to have higher rates of hepatitis B, as the infection can pass from the mother to the child during birth.² As such, individuals and children of those who come to the U.S. from these regions may have higher rates of hepatitis B than do their similarly situated peers. These high rates are reflective of things like high healthcare costs and a lack of healthcare infrastructure available to the general population from these areas, including among those who choose to come to the U.S.⁴

Detailed data collection reveals within-group disparities

As illustrated in Figure 1, the average annual rate of reported chronic hepatitis B infections in Oregon during 2021–2024 was 43.7 per 100,000 people who identified as Asian. When

Figure 2: Among Asian persons, the highest rates of reported chronic hepatitis B infection are among people who identified as **Vietnamese, Cambodian, Chinese, Laotian**, or from the **Communities of Myanmar**.



Data source: Orpheus, 1/21/2025; American Community Survey (ACS) 5-year Public Use Microdata Sample (PUMS) population estimates 2017–2021

compared to other racial and ethnic groups, this rate is striking. For example, the next highest rate of reported chronic hepatitis B infections was among people who identified as Native Hawaiian and Pacific Islander, at 30.2 per 100,000. For comparison, the statewide average is 5 per 100,000.

The aggregate rate highlights the disparity but masks important differences in the epidemiology of chronic hepatitis B within the broader Asian category.

In Figure 2, differences in the rate of infection across populations within the Asian category are apparent. Those who identified as being Vietnamese, Cambodian, Chinese, Laotian, or from the Communities of Myanmar all had chronic hepatitis B infection rates higher than the average rate among Asians. Alternatively, those who identified as Korean, South Asian, Filipino, or Asian Indian had rates lower than the average for the overall Asian category. Rates were not calculated for groups with fewer than six cases or for free-text responses. Fewer than six cases were reported among people who

identified as Japanese. Free-text response groups in the Asian category include people who identified as Afghan Asian, Asian American, Indonesian, Kyrgyz, Taiwanese, Thai, and Uzbek.[†]

These data illustrate the importance of collecting granular data on race and ethnicity; they show significant differences in rates of chronic hepatitis B among persons of different racial or ethnic identity. This is in line with variations in rates of hepatitis B that are documented both across Asia and among those who come from Asia to the U.S.^{2,6} Understanding these differences and the structural, socioeconomic factors which underpin those differences is essential to reducing those high rates of infection.^{4,8} By better understanding historical and contextual factors, this information could be used to develop public health interventions alongside the communities most significantly affected who now live and

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seek care in Oregon.

Role for clinicians

Collecting data at a more granular level helps clinicians understand the disease risk within their patient populations, tailor communications and identify new partners within the community. Clinicians have a vital role in ensuring that these data are collected as they interface with patients.

For more on REALD & SOGI data collection, please refer to the [OHA Equity & Inclusion Division's REALD & SOGI provider and partner resources](#).

For more information on some of the Oregon laws pertaining to data collection granularity, see below:

- [House Bill 2134 \(2013 legislative session\)](#), codified in Oregon Revised Statute ([ORS 413.161](#)), and the subsequently adopted Oregon Administrative Rules (OARs), require OHA to collect data on race, ethnicity, disability status, and preferred language (REALD) in a way that is uniform across all collection methods including surveys, records and reports.
- [House Bill 3159 \(2021 legislative session\)](#) amended ORS 413.161, requiring providers to collect information on REALD and sexual orientation and gender identity (SOGI) from individuals annually once the data system is built.

Examples of REALD & SOGI reporting

- [Medicaid Demographic Report](#)
- [OHA's 2022 Coordinated Care Organization \(CCO\) Performance Metrics Dashboard](#)

- [OHA's Monkeypox \(Mpox\) Data Dashboard](#)
- [OHA's COVID-19 REALD Report](#)

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*Individuals who test positive for hepatitis B in Oregon are contacted by a public health representative who collects information about the individual, including information about their race and ethnicity. Respondents who identify as Asian are asked to self-select into one of the more granular Asian categories displayed in Figure 2. Those who did not identify with any of the listed categories could select “Other Asian” and were given the opportunity to further clarify their race and ethnicity in a free text field. After analyzing these free text responses, we found that we were able to group some respondents with existing categories. Other responses, however, could not be grouped with existing categories.

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