

Collection of Race and Ethnicity Data by State Medicaid Agencies and Health Plans

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From September to December 2022, NORC conducted semi-structured virtual interviews with states and managed care organizations to understand their health equity-related data collection efforts and initiatives, successes, and challenges. This brief presents findings related to collection of race and ethnicity data in Medicaid.

This brief draws from findings from a full report related to the collection of data to advance health equity, available [here](#).

State Medicaid agencies and Medicaid managed care organizations (MCOs) have been actively developing and implementing meaningful initiatives to advance health equity, including improving the collection and use of race and ethnicity data to identify and measure health disparities and inform health equity initiatives. NORC conducted interviews with 26 representatives from 12 states and 10 representatives from 5 MCOs from September to December 2022 to understand how they are collecting and using race and ethnicity data to advance health equity.

States are collecting and disaggregating data by race and ethnicity to identify disparities and inform health equity initiatives.

In 2022, [NORC analyzed](#) the state of the quality of race, ethnicity, and language data across states and best practices for states with higher quality data.

State Medicaid leaders increasingly recognize the importance of capturing enrollees' multifaceted and intersectional identities through collection of accurate race and ethnicity data. Most states have broad goals of disaggregating data by race and ethnicity to inform development of initiatives to reduce or eliminate health disparities. Several disaggregate their Healthcare Effectiveness Data and Information Set (HEDIS) measures by race and ethnicity to assess disparities in health outcomes, including on prenatal care, cholesterol ratings,

screenings, asthma, dental care, child and adolescent well visits, and women's and maternal health.

"How do we ensure that an individual or a family who identifies as US-born African American versus Liberian African American versus Somalian African American shows up the same way in our data and the Department of Education's data and the Department of Health's data, Labor's data. I think there's work to be done there and an opportunity to be community-led in that perspective."

– Minnesota

KEY CHALLENGES WITH RACE AND ETHNICITY DATA COLLECTION AND USE

Standard guidelines for reporting race and ethnicity limit inclusivity for some populations.

State interviewees noted that Medicaid enrollees' identities do not align with existing, broad racial and ethnic categories. Standard guidelines for collecting race and ethnicity on the [U.S. Census](#) and [Transformed Medicaid Statistical Information System \(T-MSIS\)](#), which are based on the [Office of Management and Budget \(OMB\)](#) racial and ethnic categories, do not fully capture the nuances, intersections, or personal experiences of racial or ethnic identity.

“The problem of different reporting standards... We always bump against existing federal standards. So providers have to either report in a different way to us and then report in a different way for other federal commitments and that sometimes creates the so-called administrative burden to have to set up systems, to do multiple things and that creates some resistance in wanting to do what we are asking of them to do.”

– Oregon

Availability of race and ethnicity data in Medicaid enrollment applications is limited.

Most Medicaid enrollee-level demographic information comes from Medicaid enrollment files. However, federal requirements do not allow states to require applicants to report any data beyond what the state will use to determine eligibility, which excludes race and ethnicity. This policy aims to limit the ability of states to discriminate against racial or ethnic minoritized groups. However, it results in missing or incomplete race and ethnicity data, leading to challenges understanding health disparities among Medicaid enrollees, which states use to establish their health equity goals.

Technical workflows using closed-ended or hard-coded categories for race and ethnicity limit states' ability to expand their categories to better suit Medicaid enrollees' self-reported identity.

Enrollee-level information on race and ethnicity from state enrollment applications feed into other data systems at the MCO, state, and federal level, including to inform models for reimbursement, distribution of healthcare resources, and program planning. The interconnected nature of these data systems limits the opportunity for open-ended responses or nuance in how states categorize race and ethnicity for their Medicaid enrollees.

Poor data quality (including incomplete, missing, or inaccurate data) leads to misunderstanding of health disparities.

Rigid and broad racial and ethnic categories may lead to misrepresentation of populations and communities in data if they limit the ability of a Medicaid enrollee to identify in a way that reflects their full experience, potentially negating or hiding critical aspects of their health needs or concerns. They also limit states' abilities to disaggregate data, which can create inappropriate conflation of groups with meaningful differences (e.g., between US-born Black and Black immigrant populations). These limitations lead to poor data quality as a person's identify is miscategorized

or missed, masked nuances in inequities, and a limited view of enrollees' full needs and lived experience.

Privacy concerns can limit data sharing to support health equity. HIPAA protects patient health information from abuse or disclosure; [42 CFR Part 2](#) protects patient records on substance use disorder. Interviewees spoke about the challenges that these privacy protections can pose for data sharing and data quality. For example, [HIPAA 834](#), a standard file format for transmitting data, can limit MCOs' ability to collect or report data in different ways as they follow standard reporting requirements for transmitting data. MCO interviewees also expressed a lack of clarity about what data they can or cannot share with non-medical providers like community health workers. Interviewees also noted that there is general provider hesitancy to share any health information that they may perceive as sensitive, even if it is allowable for sharing under HIPAA.

Sexual Orientation and Gender Identity (SOGI) Data Collection Challenges

States are also interested in advancing health equity efforts related to members' SOGI. Rigidity in how states and federal government collect these data and potential privacy concerns limit providers and Medicaid program's ability to understand important disparities and experiences of SOGI minoritized members. Improving states' and MCOs' ability to collect SOGI data is another priority for state Medicaid programs.

EFFORTS TO IMPROVE COLLECTION OF RACE AND ETHNICITY DATA

States are updating their Medicaid enrollment applications to better reflect enrollees' race and ethnicity.

Some states are focused on enhancing the phrasing of race and ethnicity questions in state applications, providing explanations on why they are collecting these data, and improving their data systems to better reflect race and ethnicity. For example, Oregon expanded its race, ethnicity, language, and disability status (REALD) questions to include a primary race question, an open-ended question for respondents to identify their race in any way (helps to identify emerging populations), and one additional question with 39 response categories to enhance the state's ability to disaggregate data down to specific populations. They will use these data to inform policies to identify and eliminate inequities.

States use Medicaid managed care contracts to drive more equitable outcomes and encourage accountability.

This includes through:

- **Measure reporting:** Most states have begun to evaluate the status of health equity in their programs by requiring MCOs to stratify and report select Medicaid Core Set quality measures by race and ethnicity. Measure selection approaches differ across state and MCOs. A combination of state and MCO health equity goals guide their choice of measures selected for stratification for priority populations. Some select specific subsets of measures based on priority areas while others take a broader approach to stratify globally across measure sets. Most stratified measures focus on clinical outcomes and utilization domains with evidence of disparities, including child and maternal health, chronic conditions, and access to care.
- **Payment models.** Some states are rolling out programs to incentivize hospitals and Accountable Care Organizations (ACOs) to improve race and ethnicity data collection and meet certain quality targets tied to health equity goals. For example, Massachusetts, through its approved MassHealth Section 1115 waiver, will financially incentivize ACOs and ACO-participating hospitals to provide complete data on race and ethnicity, disability, and SOGI data starting in fiscal year 2023.
- **Health Equity Accreditation.** Some states and health plans view the National Committee for Quality Assurance (NCQA)'s Health Equity Accreditation as a path forward to set standards around fundamental race and ethnicity data capabilities to advance health equity. South Carolina requires contracted health plans to obtain the health equity accreditation. They view the accreditation as way to set standards around fundamental race and ethnicity data capabilities to advance health equity.

MCOs' and providers' direct contact with Medicaid members can enhance race and ethnicity data.

Providers are often Medicaid members first point of contact with the healthcare system. MCOs and providers can also collect data at every point they interact with a member. Through these various points of contacts, providers and MCOs can update members' race and ethnicity information to ensure it is accurate or fill in missing data and can share that data back to their state Medicaid programs.

States rely on, aggregate, and link multiple sources of data to get the most comprehensive and accurate picture of each Medicaid enrollee, particularly to supplement missing race and ethnicity data.

Both states and MCOs rely on Medicaid enrollment data and eligibility files for eligibility and demographic information as the original "source of truth" for a Medicaid enrollee's data. However, states use additional data

sources to supplement missing data. For example, data from the Department of Children and Families, Department of Health, Department of Human Services, or Vital records. Some states and MCOs also collect data through surveys such as risk assessments.

ADDITIONAL SUPPORTS AND NEEDS

States and plans highlighted a need for national standards for collecting, analyzing, and monitoring race and ethnicity data.

This is already in motion, to some extent, with the CMS and federal calls for more robust collection of this data and OMB's recently proposed changes to its racial and ethnic categories, intended to better capture the identities of Americans. However, interviewees highlighted the need for CMS and the Department of Health and Human Services (HHS) to ensure that these standards can be validated across systems and allow for more robust and accurate representation of race, ethnicity, and language data from members. This requires that CMS providers the following:

- A thorough explanation to Medicaid members as to why race and ethnicity and SOGI data is being collected.
- Guidance and support to states for collecting and analyzing data, including technical assistance to disaggregate race and ethnicity and SOGI categories.
- Regulations and standards for interoperability.
- Incentives to collect race and ethnicity data.

States and plans also highlighted a need for federal support to coordinate and harmonize technological systems.

Part of making race, ethnicity, and SOGI data interoperable will include addressing issues surrounding HIPAA and establishing guidance and support around exchange of information and reporting of members data. This involves aligning systems so providers can submit information on members to one source instead of multiple sources. CMS can take a more consistent role in how data is collected, analyzed, and interpreted at the state and federal level. Best practices are also needed so states can see examples of how states collect and interpret data from historically marginalized communities.

Methodology

From September to December 2022, NORC conducted semi-structured virtual interviews with 26 representatives from 12 states and 10 representatives from 5 health plans. NORC selected states based on geographic and Medicaid program diversity and known information about Medicaid program progress in advancing health equity. NORC worked with the Association of Community Affiliated Plans (ACAP) to identify health plans for the interviews.

Topics of discussion included:

- Data collection efforts states and plans were engaged in to support measurement and oversight of health equity goals in Medicaid
- How states and plans were developing data collection systems to monitor health equity measures, e.g., health disparities, social risk factors, and demographics like race, ethnicity, and language
- Success/facilitators and challenges/barriers states and health plans were facing when developing or implementing data and systems-level approaches to collecting health-related social needs and race, ethnicity, language data
- Additional policies and supports states and health plans need to improve their data collection efforts to advance health equity

We recorded each interview for note-taking purposes. To analyze the data, NORC used NVivo qualitative data software to code each transcript. NORC developed a code book inductively based on the interview guides and research questions and updated the codebook inductively based on emerging themes from the coding process. The NORC team conducted thematic analysis of the themes to synthesize findings.

Participating states: California, Florida, Hawaii, Massachusetts, Michigan, Minnesota, Oregon, Pennsylvania, Rhode Island, South Carolina, Tennessee, and Washington

Participating health plans: Health Plan of San Joaquin, Community Care Plan, Hennepin Health, CareOregon, Neighborhood Health Plan of Rhode Island

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