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Data Collection in Medicaid to Advance Health Equity:

Findings from Interviews with State Medicaid Agencies and Managed Care Organizations

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Executive Summary

Introduction

Accurate and quality data are critical to advancing health equity. Data provides state Medicaid programs and Medicaid managed care organizations (MCOs) with a more accurate depiction of the health and social needs, health outcomes, and disparities experienced by their enrollees. Higher quality data better equips states and MCOs to develop data-driven, meaningful enhancements to services and address inequities in healthcare access and outcomes.

From October to December 2022, NORC at the University of Chicago conducted semi-structured interviews with 26 individuals representing 12 state Medicaid agencies and 10 individuals representing 5 MCOs. The interviews sought to understand what measures and overall data collection efforts states and MCOs are engaging in to support their health equity goals.

Key Findings

Updating race, ethnicity, language, disability (REALD), and sexual orientation and gender identity (SOGI) categories more accurately captures inequities in enrollee needs and outcomes.

States and MCOs use data to identify disparities among their enrollees and inform development of initiatives to advance health equity, particularly efforts focused on racial-ethnic minoritized communities. However, they experience various challenges with data collection, including:

- current federal guidelines for broad categories of reporting race, ethnicity, and SOGI can limit inclusivity by not reflecting all the ways in which people identify, which can lead to poor data quality.
- per federal requirements, states cannot require applicants to report data beyond what the state will use to determine eligibility, which excludes race and ethnicity. This results in missing or incomplete race and ethnicity data in Medicaid enrollment applications.

Nevertheless, state Medicaid and MCO leaders increasingly recognize the importance of understanding the experiences and needs of enrollees with multifaceted and intersectional identities through revised race and ethnicity categories. Multiple state Medicaid programs and MCOs are updating how they ask about race and ethnicity in applications to enhance the quality of and disaggregate data.

Aggregating data across multiple sources helps states and MCOs get a more comprehensive picture of enrollee needs and outcomes.

States rely on multiple sources of data to get the most comprehensive and accurate picture of each enrollee, particularly for missing race and ethnicity data. However, states and MCOs noted a need for a more uniform strategy and standards to collect, analyze, interpret, and monitor REALD, health-related social needs (HSRN), and SOGI data given the following challenges:

- a lack of standardization results in inconsistent or contradictory data on Medicaid enrollees' race and ethnicity across data sources (e.g., across public programs or applications, MCO data, provider data).
- technical workflows with closed-ended or hard-coded race and ethnicity categories can limit states' ability to expand their race and ethnicity categories to better reflect Medicaid enrollees' self-reported identity and share data across systems.
- a lack of standards for tracking and reporting HRSN can lead to a fragmented or incomplete understanding of enrollee-level needs.
- though Z codes could serve as a potential avenue for standardizing HRSN data, there are no requirements, incentives, or standard practices for their use.
- challenges with data privacy protections like HIPAA and 42 CFR Part 2, while designed to protect patients, can limit states' ability to share data on important health needs or patient characteristics.

States and MCOs noted a need for national REALD, HSRN, and SOGI standards that can be validated across systems to standardize definitions and promote data linkage and aggregation. Legal and data sharing agreements between states and MCOs help them overcome regulatory or legal hurdles that limit data sharing.

Enhancing data infrastructure helps departments and staff have the tools they need to collect and run analyses to advance health equity.

States rely on both internal and external data infrastructure to support their efforts. This includes in-house and external data warehouses like all payer claims databases and health information exchanges. States and MCOs facilitate technical assistance to support internal and external data related systems and processes to guide collection of race/ethnicity and HRSN. Some are also transforming organizational culture and operations to ensure internal capacity-building activities are happening across the entire organization and at every level. However, states described challenges with technological capacity, particularly related to capturing HRSN and support closed loop referral systems. States and MCO interviewees noted a need for more resources, investment, and time for establishing and synchronizing data systems and infrastructure and supporting their workforce.

Using delivery system levers improves state, MCO, and provider accountability for improving data collection to advance health equity.

States leverage managed care contracts as a vehicle to drive more equitable outcomes and encourage provider accountability towards progress reducing inequities in outcomes. They use these contracts to require MCOs to submit data on race, ethnicity, and HRSN. Over half of participating states require MCOs to maintain National Committee for Quality Assurance Health Plan Accreditation to standardize quality; a few require Health Equity Accreditation. States also use payment models (e.g., pay-for-performance), quality withholds, and other incentives to encourage improved quality of health equity data collection and reporting. Data dashboards,

public facing reports, and sharing data back with MCOs and providers increases accountability for progress in improving data collection to advance health equity.

Engaging state leadership and community members garners buy-in for health equity data collection efforts.

With finite time, resources, and capacity, states need a cohesive strategy for applying data to inform health equity program and policymaking and establishing priorities. States noted that competing or evolving priorities can make it difficult for states and providers to keep health equity data collection efforts at the forefront. Garnering leadership buy-in and political will is important but can be a challenge, particularly amid competing priorities. Without leadership buy-in and support, some state interviewees noted they have faced provider resistance in engaging in data collection efforts. Having state executive leadership promote systemic health equity efforts is critical for buy-in across staff, including promoting provider buy-in. States stressed the important roles of governors, legislatures, and executive level state agency staff in setting a clear strategy and vision for health equity. States and MCOs also highlighted the role of community engagement in improving data quality. MCOs' and providers' direct contact with Medicaid enrollees can also aid in enhancing data collection.

Conclusion

States and MCOs have made substantial headway in thinking about how to advance their data collection to improve health equity. State Medicaid leaders increasingly recognize the importance of understanding the experiences and needs of enrollees with multifaceted and intersectional identities through revised race and ethnicity categories and other data collection mechanisms. They are implementing efforts to enhance the quality to inform development of health equity initiatives in their states and organizations.

However, federal guidelines for reporting REALD and SOGI, poor data quality, privacy concerns, lack of standardization, and competing priorities can make it difficult for states and MCOs to collect the data they need to inform their efforts. Nevertheless, states are working with other state agencies, MCOs, and providers to share data and aggregate data across multiple sources. They are also leveraging delivery system levers like MCO contract requirements and pay for performance to hold MCOs, providers, and ACOs accountable for progress towards advancing health equity. States are also working with leadership to establish a culture of health equity and enhance their infrastructure to support data systems and processes. Overall, states and MCOs acknowledge that data are critical to advancing health equity for Medicaid enrollees and are taking steps to improve the quality and accuracy of their REALD and SOGI data.

Full Report

Introduction

State Medicaid programs serve diverse populations that experience the disproportionate impact of structural racism and other inequities that impact their experience with providers and the healthcare system, outcomes, and access to care.¹ State Medicaid programs and Medicaid managed care organizations (MCOs) can use initiatives aimed at advancing health equity efforts to improve enrollee satisfaction, engagement, and use of preventive services, and reduce the utilization of unnecessary care.^{2,3}

Accurate and quality Medicaid data are critical to advancing health equity as it provides state Medicaid programs and MCOs with a more accurate depiction of the needs, health outcomes, and disparities experienced by their enrollees based on race, ethnicity, and other characteristics. Higher quality data better equips states and Medicaid MCOs to leverage the information they collect from their enrollees to develop data-driven, meaningful enhancements to services and address inequities in healthcare access and outcomes.^{4,5} Developing data collection strategies to advance health equity is a priority for the Biden administration and the Centers for Medicare and Medicaid Services (CMS).^{4,5} CMS highlights the need to improve the collection, reporting, and analysis of individual-level demographics including race, ethnicity, language, and disability status (REALD), sexual orientation and gender identity (SOGI), and health-related social needs (HRSN) to improve quality and promote equitable access to healthcare services and coverage in its [Framework for Health Equity](#).

NORC at the University of Chicago (NORC) interviewed representatives from state Medicaid agencies and MCOs to understand how they use data to advance health equity. We assessed:

- What measures and overall data collection efforts states and MCOs are engaging in to support health equity goals in Medicaid.
- How states and MCOs are developing data collection systems to monitor health equity measures, e.g., HRSN, race and ethnicity, and SOGI.
- What successes and challenges states and MCOs face when developing or implementing systems-level approaches to collecting data.
- What additional policies and supports states and MCOs need to improve their data collection efforts to advance health equity.

Methods

NORC conducted semi-structured, 45-to-60-minute virtual interviews with state Medicaid program officials and MCO staff. We used [prior work](#), existing relationships with state staff, and publicly available information to identify diverse states in terms of geography, types of Medicaid programs, and in different stages of progress in implementing health equity data collection

initiatives and goals. One participating state also recommended additional states for interviews. For MCOs, NORC worked in partnership with the Association for Community Affiliated Plans (ACAP) to identify Medicaid MCOs located in states that participated in interviews for the study.

From October to December 2022, NORC conducted outreach to state Medicaid directors and other Medicaid staff (e.g., Medicaid eligibility and enrollment officers, IT staff, health equity leads) in 15 states. Twenty-six individuals representing 12 state Medicaid agencies (80% response rate) participated in interviews (Exhibit 1). ACAP conducted warm handoffs between six MCO leads and NORC, with NORC performing outreach to one additional MCO. NORC conducted interviews with 10 individuals in five of the seven MCOs (71% response rate).

Exhibit 1: List of Participating States and MCOs

State	Participating State Agency(ies)	Participating MCOs
California	Department of Health Care Services	Health Plan of San Joaquin
Florida	<ul style="list-style-type: none"> ▪ Agency for Health Care Administration ▪ Florida Department of Health 	Community Care Plan
Hawaii	State of Hawaii, Department of Health and Human Services, Med-QUEST Division	N/A
Massachusetts	MassHealth	N/A
Michigan	Department of Health and Human Services	N/A
Minnesota	Department of Human Services	Hennepin Health
Oregon	Department of Human Services, Oregon Health Authority	CareOregon
Pennsylvania	Department of Human Services	N/A
Rhode Island	Office of Health and Human Services	Neighborhood Health Plan of Rhode Island
South Carolina	Department of Health and Human Services	N/A
Tennessee	TennCare	N/A
Washington	Health Care Authority	N/A

NORC recorded all interviews for note-taking purposes. We used NVivo qualitative data software to code transcripts from the interviews. We developed a codebook based on the interview guide and study research questions, and updated the codebook based on emerging themes during the coding process. All team members coded a sample transcript and participated in a discussion to achieve consensus on interpretation of codes. We conducted thematic analysis to identify and synthesize key themes across interviews.

Key Findings

This section describes key findings across interviews on how states and MCO are undertaking initiatives to improve health equity data collection and the challenges they have encountered in implementing these efforts.

Updating REALD and SOGI categories more accurately captures inequities in enrollee needs and outcomes

States and MCOs use data to develop health equity initiatives, particularly efforts addressing disparities experienced by racial-ethnic minoritized communities.

Interviewees noted that Medicaid can enforce policies, set standards, and delineate strategies for how and when to collect REALD, HRSN, and other data. They also noted that Medicaid can help translate data in a digestible way so that all entities involved in serving Medicaid enrollees can make informed data-driven decisions and initiatives to address health disparities and improve population health. MCOs can also develop interventions or initiatives based on identified gaps found in health outcomes. They can identify common drivers of health or social needs by stratifying by key demographics such as race/ethnicity and SOGI.

“[Medicaid is] responsible for helping to ensure the best quality outcomes possible for our members. And that includes not just caring about if they have access to good hospitals and good doctors, but, also, are there other needs, are there other inequities out there that we can help to mitigate? So collecting this data allows us to see where those issues are and hopefully intervene or provide support to mitigate where those issues are. But we can’t do that until we actually have the data that helps us to see it, instead of just making assumption.”

– TennCare

Several state and MCOs disaggregate their Healthcare Effectiveness Data and Information Set (HEDIS) measures by race and ethnicity to assess disparities in health outcomes. This includes measures on prenatal care, cholesterol ratings, screenings, asthma, dental care, child and adolescent well visits, and women’s and maternal health. Several states are building initiatives that focus on SOGI, maternal and child health, HRSN, and behavioral health disparities.

State Medicaid Initiatives to Address Racial Disparities in Health and Health Care

In Kaiser Family Foundation’s annual Medicaid budget survey, [41 of 46 states](#) reported at least one Medicaid initiative to address racial health disparities in a specified area, such as maternal health, behavioral health, COVID-19, cancer, chronic conditions, or justice-involved populations).

State and MCO Highlights

- The State of **Hawaii** Department of Health and Human Services, Med-QUEST Division focuses on eliminating disparities in maternal and child health and improving health outcomes for Native Hawaiian pregnant women, with a focus on mental health and substance use. The state partners with community centers to share data and requires health plans to track outcomes relating to disparities.
- Minnesota’s **Hennepin Health** is a pilot site with HEDIS, layering race and ethnicity data against HEDIS measures to analyze health disparities on about 50-70 metrics.
- **Pennsylvania** and **Michigan** tie incentives to progress on health equity related HEDIS measures, such as progress closing racial and ethnic disparities in prenatal care and cholesterol ratings.

“Talking about health disparities, race, ethnicity and language, and social drivers of health—those are distinctive things. So just to talk about social drivers of health does not mean that you’re addressing health disparities. While they are related, they are not the same thing. You still have to be explicit and intentional if you are wanting to address health disparities in each of these areas.”

–State of Hawaii, Department of Health and Human Services, Med-QUEST Division

However, federal guidelines for race, ethnicity, and SOGI data and state Medicaid application requirements pose challenges for collection of more nuanced identity data.

Standard guidelines for reporting race, ethnicity, and SOGI can limit inclusivity for some people. Interviewees noted that Medicaid enrollees’ identities do not always 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 \(OMB\)](#) guidelines, are not always inclusive of the nuances, intersections, or personal experiences of racial and/or ethnic identity. This may lead to misrepresentation of populations in data if they limit the ability of a Medicaid enrollee to identify in a way that reflects their full experience. 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

OMB Standards and Potential Changes

Current OMB racial categories are White, Black or African American, American Indian or Alaska Native, Asian, Native Hawaiian or Other Pacific Islander and Other for race. OMB recommends a separate Hispanic or Latino ethnicity question.

In January 2023, OMB released a [request for public comment](#) on proposed updates to federal race and ethnicity standards to acknowledge the increasing racial and ethnic diversity, the growing number of individuals who identify as multiple races or ethnicities, and the changing immigration and migration patterns. Changes include: a combined race/ethnicity question; a new option for Middle Eastern and North African populations; and asking for more detailed responses on people’s identities.

immigrant enrollees). These limitations result in poor data quality; if a person’s identity is miscategorized or missed, this can negate or hide critical aspects of their health needs or concerns. However, OMB recently proposed changes to its race and ethnicity categories to better capture the identities of Americans.⁶

“People who are Latino will say, ‘Well, I’m neither white nor Black; I’m Latino’... We know the Census separates race and ethnicity... But I’m not sure that’s the way the general public looks at it. So when we start looking more and more at race-ethnicity data, we have the longstanding way of how the data has been collected versus how people perceive themselves and identify. And I think if we don’t have that connection, then we could be missing things. We’re misidentifying issues. We’re misidentifying people’s circumstances because the categories we have now aren’t the categories that people perceive themselves as, especially as we have more people who may identify as biracial or multiracial.”

– Pennsylvania Department of Human Services

A similar challenge exists for SOGI data. States and MCOs are in earlier phases of collecting more nuanced SOGI data than they are for race and ethnicity data. However, as a few states consider or begin to implement data collection that is more expansive and inclusive of the broad range of enrollees’ SOGI, they have encountered challenges in how these data are historically structured and collected, which may misalign with people’s self-identification.

In addition, federal requirements for state Medicaid enrollment applications can limit the quality of race and ethnicity data states and MCOs receive. Most Medicaid enrollee-level demographic information comes from Medicaid enrollment files. However, per federal requirements, states cannot require applicants to report any data beyond what the state will use to determine eligibility such as race and ethnicity.⁷ This policy aims to limit the ability of states to discriminate against racial or ethnic minoritized groups. In practice, though, it results in missing or incomplete race and ethnicity data, limiting states’ ability to use Medicaid enrollment files to understand where health disparities exist. This can cause challenges in creating a truly comprehensive picture of health disparities among Medicaid enrollees, which states use to establish health equity goals. As states set goals for closing disparities in health services and outcomes between racial and ethnic groups, it is important for them to have an accurate representation of both the baseline differences between groups and any progress made in advancing health equity as they implement strategies.

Quality of Race and Ethnicity Data in T-MSIS

Race and ethnicity data in Medicaid applications are of mixed quality. A [NORC report](#) highlights how states’ data completeness and quality in T-MSIS has changed over time. It also highlights key features across states with low concern in their data quality and recommendations for improving collection of race and ethnicity data in applications.

Multiple state Medicaid programs and MCOs are updating how they ask about race and ethnicity in applications to enhance the quality of and disaggregate data.

Nevertheless, state Medicaid and MCO leaders increasingly recognize the importance of understanding the experiences and needs of enrollees with multifaceted and intersectional identities through revised race and ethnicity categories. They noted that concepts of race, ethnicity, and identity continue to evolve, highlighting the importance of revising existing race and ethnicity categories to better capture the identities of their enrollees. Further, there will always be a need to unpack the complexities of racial and ethnic categories, as they are facets of identity that are socially constructed but hold real-life consequences for health and well-being. 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, ethnicity, and SOGI.

Improving Race/Ethnicity Data in Medicaid Applications

[Twelve of 45](#) states reported in Kaiser Family Foundation’s annual budget survey that they explain how race and ethnicity data will be used and why they are important in their eligibility and renewal materials and applications. Five reporting having state enrollment broker call center scripts that encourage self-reporting of race and ethnicity data. Several translated the application to other languages, added disability and SOGI to applications, changed the phrasing of questions, and allowed applicants to give more detailed race and ethnicity information.

“What we have seen is that, as a state, we can look OK in a measure but, when we disaggregate it by race and ethnicity, we start to see disparities and recognize that there are issues with some of the health outcomes based upon race and ethnicity.”

– Pennsylvania Department of Human Services

State and MCO Highlights

- California’s **Health Plan of San Joaquin** and Florida’s **Community Care Plan** are interested in incorporating SOGI within their data collection efforts.
- **Oregon** expanded its 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.

Aggregating data across multiple sources helps states and MCOs get a more comprehensive picture of enrollee needs and outcomes

States rely on multiple sources of data to get the most comprehensive and accurate picture of each enrollee, particularly for missing race and ethnicity and HRSN data.

States link to additional data sources to supplement missing data, particularly race, ethnicity, and HRSN data. Both states and MCOs rely on Medicaid enrollment data and eligibility files for

eligibility and demographic information as the original “source of truth.” However, states supplement this data with data from other state agencies including vital records, child welfare information, other health information, and data from programs like Temporary Assistance for Needy Families (TANF), Supplemental Nutrition Assistance Program (SNAP), Women, Infant, and Children (WIC), and Low Income Home Energy Assistance Program (LIHEAP). These data sources help states gain a more comprehensive picture of Medicaid enrollees’ HRSN.

Some states also leverage data, including race and ethnicity data, from their providers and MCOs that report data to the state for quality improvement programs or as part of pay-for-performance (P4P) programs. State interviewees noted that working with MCOs, accountable care organizations (ACOs), and providers can help states have more detailed and updated information on enrollees given they typically have a closer relationship to enrollees than the state itself. Since providers are often Medicaid enrollees’ first point of contact with the healthcare system, they can take a more proactive role in assessing for HRSN via social needs assessments. MCOs and providers also collect data on members more frequently (e.g., at every point they interact with an enrollee) than states and thus have more timely data. Some states and MCOs also do their own primary data collection through surveys or health risk assessments. These states and MCOs noted they believe self-reported enrollee data are often the most accurate.

Aggregating and Linking to Improve Race and Ethnicity Data

[Nine of 45](#) states reported linking Medicaid enrollment data with public health department vital records data and 8 reported partnering with health information exchanges to obtain additional race and ethnicity for Medicaid enrollees in Kaiser Family Foundation’s annual budget survey. Multiple reported using other data sources like administrative records from other agencies or third-party databases.

“We have used our Medi-Cal application as our source of truth, because it’s supposed to be filled out by the beneficiary... So they should be self-identifying in the way they want to for their race, ethnicity, sex, sexual orientation, gender identity, etc... And then we go to various other reporting.”
 – California Department of Health Care Services

State and MCO Highlights

- **California** links their Medicaid data in their data warehouse with child welfare data to support analysis and public reporting by the Medi-Cal program and by the Department of Social Services. California currently has a data exchange and linkage process with the California Department of Corrections to support the [Medi-Cal Utilization Project](#). California also passed statute and is implementing the [Data Exchange Framework](#), which includes requirements for managed care plans to exchange data by January 31, 2024.
- **MassHealth** links data in its Medicaid data warehouse to data from other state agencies, including the Department for Children and Families.
- **Michigan** uses a master person index to link to other data sources including unemployment data.

- **Pennsylvania’s** data warehouse uses a unique identifier to track services its Medicaid enrollees use across state agencies, including child welfare, SNAP, TANF, LIHEAP, and housing assistance programs.
- **Rhode Island** aggregates data from community partners addressing homelessness. To improve data quality, **Neighborhood Health Plan of Rhode Island (NHPRI)** links race and ethnicity data from COVID-19 vaccination data, health risk assessments, and the child immunization registry to their enrollment file data. This resulted in availability of race and ethnicity for 88 percent of their members, up from 50 percent.
- **South Carolina** has a data hub with linked data sets across some state agencies including the Department of Health and Environmental Control, the Department of Social Services, and the Department of Mental Health.
- **Tennessee** is working towards a unified data hub across all state agencies to help focus priorities in the state, for example tackling the opioid epidemic.

A few states and MCOs link to other publicly available, external data sources or impute data to fill data gaps, particularly for HRSN. Interviewees noted that the use of publicly available data sources can help them better understand member experiences and community resources. Others noted that data imputation can fill gaps in missing or incomplete data. However, they acknowledged imputation is not a comprehensive solution that they can apply equally across all groups. Some interviewees cautioned against imputation of race and ethnicity as it can further contribute to mis-categorization of people’s identities and misunderstanding of their health or social needs.

State and MCO Highlights

- **Neighborhood Health Plan of Rhode Island** uses publicly available geospatial information and mapping to understand transportation barriers in lieu of having a complete dataset on member needs for transportation support.
- **Washington State** is exploring multiple external data sources such as IBM Watson, American Community Survey, and census data to understand the HRSN of their members. In addition, Washington State has partnerships with the University of Washington where they are using modeling tools to analyze the impacts of climate change within the Medicaid population, and a partnership with their enterprise data warehouse to geo-code their information for future use in other initiatives.

“[One of our health plans felt] imputed data was fairly accurate when it came to identifying African Americans and White [persons]. But it had a lot of errors when they were identifying Asian Americans. And they’re not sure why, but they’re looking into that. So that’s one of the reasons that, when they do their health-equity report, they’re going to rely only on self-reported data that comes from the TennCare eligibility system. We know that there will always be a gap there because it’s not required for individuals to tell us. To fill in the rest of the gap I think we, or the MCOs, will ultimately have to rely on other data resources, and they’re going to have to get to a point where they really trust that that’s accurate enough.”

– TennCare

However, lack of standardization, technical workflows, and privacy considerations create challenges for states aggregating or linking data across data sources.

Reconciling state Medicaid data with that of other agencies is a challenge due to inconsistencies in data. Interviewees reported that there are often inconsistent or contradictory data on Medicaid enrollees’ race and ethnicity across data sources. Many states do not have a single, standard data collection system or process across agencies, resulting in differences or discrepancies in reported racial or ethnic identity in Medicaid enrollment data compared to data collected or managed by other state offices and departments. This is also true across different governmental and jurisdictional levels within the state such as counties or localities. For example, various state interviewees discussed how Medicaid program collect race and ethnicity data differently than education or child welfare agencies. These data are also often not uniform across MCOs, within MCO internal systems, or within an entire MCO provider network.

“I’m dealing with T-MSIS... and we have one set of standards for race, ethnicity, gender. That can be very different from what you see in vital records, which can be very different from what you’re seeing in education-related items, which is very different from what you’re seeing in corrections.”

– Michigan Department of Health and Human Services

“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, and Labor’s data. I think there’s work to be done there and an opportunity to be community-led in that perspective.”

– Minnesota Department of Human Services

Technical workflows with closed-ended or hard-coded race and ethnicity categories can limit states’ ability to expand their race and ethnicity categories to better reflect Medicaid enrollees’ self-reported identity and share data across systems. Enrollee-level information on race and ethnicity from state enrollment applications feeds into other data systems at the MCO, state, and federal level, including to inform models for reimbursement, distribution of healthcare resources, and program planning. If state Medicaid programs broaden their race-ethnicity categories, they may have to re-categorize people’s identities based on federal reporting

requirements. Additionally, MCOs and providers also share data back to the state and the federal government about enrollee demographics. The interconnected nature of these data systems limits the opportunity for open-ended responses or nuance in how states and MCOs categorize race and ethnicity for their Medicaid enrollees when sharing data across systems.

Many states cited a lack of standards for tracking and reporting HRSN as leading to a fragmented or incomplete understanding of enrollee-level needs. State interviewees described that providers are using different screening tools, data collection systems, and platforms for making and tracking social needs referrals. While it is important to enable providers and health systems to implement tools that fit their patient needs and care management workflows, this lack of standardization makes it challenging to get a state-level understanding of enrollees’ HRSN and the extent to which those needs are being met.

State Highlights

- **Michigan** attempted to implement a standard HRSN screening tool. However, the state eliminated its use because they heard from providers that it was not capturing accurate, usable data and, therefore, was not appropriate for setting benchmarks at the state level. The state then engaged a public health institute to redesign the tool in a way that aligns with HEDIS measures on HRSN, with the goal of maximizing utility and reducing burden for collecting this data.

Some states noted that Z codes could serve as a potential avenue for standardizing HRSN data, but there are no requirements, incentives, or standard practices for their use. Z codes are ICD-10 codes that providers can use to report HRSN on claims data.⁸ They can identify a range of social, economic, environmental, and occupational factors related to health. Various state and MCO interviewees noted that while Z codes could be a useful tool for standardizing this information on Medicaid claims data, providers often lack sufficient incentives to capture and report data on HRSN to MCOs or state Medicaid agencies. Z codes are not tied to provider incentives, even if they are submitted on a claim for billing. Thus, overall provider use of Z codes is limited.⁹

Use of Z Codes in Medicaid Claims and Encounter Data

A [NORC report](#) highlights how few providers document enrollee social needs using Z codes in Medicaid claims and encounter data.

“A lot of [providers] aren’t putting [Z codes] in there. A lot of that data is being lost. It’s being captured at different settings of care, but it’s not being shared across the board to help impact that member’s care. So I think that’s the biggest challenge—where do we get that information from? Who’s able to provide it?”

–Community Care Plan

Establishing data governance systems and data sharing agreements for linking or sharing information is critical for overcoming challenges with privacy concerns. Data privacy protections like HIPAA and 42 CFR Part 2, while well-intentioned and designed to protect patients, can limit states’ ability to share data on important health needs or patient characteristics. [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. The nature of reporting requirements and data formats for MCO and state Medicaid data can limit states’ ability to innovate or evolve how they collect race and ethnicity questions to meet community needs and preferences. 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. States ultimately must piece together data sharing agreements with MCOs, health systems, and providers who all may be using different EHR systems or platforms for collecting these data.

“There are these new programs such as community support where those providers are usually non-traditional. They’re not medical providers and so, what aspects of the patient’s information can we or can’t we share with them? This becomes an issue because we want effective outreach and engagement of the patients, but we also want to do it in a way where it’s in line with what the patient expects to happen with their data. So the state’s going down that path in terms of getting permissions set up.”

– Health Plan of San Joaquin

States and MCOs noted a need for a more uniform strategy and standards to collect, analyze, interpret, and monitor REALD, HSRN, and SOGI data.

States and MCOs noted a need for federal guidance on REALD, HSRN, and SOGI standards. Developing national standards may require federal agencies to take a more consistent role in providing federal policies, guidance, and clarification around how data are collected, analyzed, and shared. Interviewees noted that this includes providing guidance, resources, and technical assistance for states and MCOs to collect and analyze this data. They also described a need for federal agencies to set regulations and standards for interoperability, data sharing, and harmonizing current technological systems. To overcome concerns around privacy, interviewees recommended that federal agencies clarify guidance around HIPAA and other regulations that manage privacy and data sharing. Interviewees also described a need for CMS to provide incentives to states, MCOs, and providers to collect REALD, HSRN, and SOGI data.

Enhancing data infrastructure helps departments and staff have the tools they need to collect and run analyses to advance health equity

States rely on both internal and external data infrastructure and provide technical assistance to providers to support their data collection efforts.

States use different methods to establish their data infrastructure. Some states have in-house data warehouses for their Medicaid information and link those to data from health information exchange (HIEs), providers, MCOs, and other state agencies. Others rely on external data warehouses, all-payer claims databases (APCDs), or HIEs to house data from various sources, which they then extract for analytic purposes. States and MCOs are facilitating technical assistance support internally and externally around data related systems and processes to guide data collection efforts on REALD and HRSN. Others are in the exploration phase of ways to provide technical assistance to providers to support collection of race and ethnicity data.

State Highlight

- **Oregon** has developed resources and tools increasing and standardizing reporting of REALD data across the Department of Human Services and the Oregon Health Authority.

“It’s resource intensive because it requires changing systems. It requires investing in developing the workforce. We have been fortunate that we have the political support and funding from the legislature and at the executive level, in terms of the governor, to allocate resources to do this work in the Oregon Health Authority... now we have a staff of almost 23 and there are other divisions in the Oregon Health Authority that have capacity to collaborate with us in doing this work because they also have additional staff. So, I would say that it’s quite resource intensive and without that you can’t go far.”

– Oregon Health Authority

Some states are transforming internal culture and operations to ensure internal capacity-building activities are happening across the entire organization and at every level. Some states are creating specific roles to advance health equity or integrating health equity into the functions of existing staff. Others crafted job descriptions specific to health equity data collection and analysis to better align job functions with health equity goals.

“As a state agency, the Health Care Authority has within our strategic plan identified very specific health equity goals. And that echoes not just particularly in a silo, but really permeates throughout our policymaking, our staffing models, our organizational structures, the policy program data, how we look at data, and how we stratify and share data for decision making with an equity lens.”

– Washington Health Care Authority

However, states described challenges with technological capacity, particularly related to capturing HRSN and support closed loop referral systems.

Provider sharing of referral information to the state, MCO, or across providers occurs on a case-by-case basis or for a specific intervention, program, or health condition. States generally do not have a universal system (i.e., one single platform used for all HRSN screening or referrals to services across a state) for coordinating care or sharing information across systems and providers, although a few have begun to investigate options for establishing this type of system. Some states use referral platforms (e.g., FindHelp) but these often do not connect back to electronic health records (EHRs). Thus, states and providers cannot consistently track which enrollees need services or if they have received support for those needs. Many state interviewees noted they wish they had a closed-loop tracking and referral system to better understand their enrollees’ HRSN. Finally, states also expressed frustration with outdated EHRs and a lack of innovative technology that would help states set goals for addressing HRSN and track that providers and service organizations are meeting enrollees’ needs.

“What we don’t currently have in place is systematic data collection... I would love to see a process whereby social risk factor questions become embedded as part of the standard screenings that Medicaid members get no matter where they go... And for there to be standard mechanisms that, as that gets recorded in the physician’s EHR or wherever they might be, that it translates into that Z code that then drops into the claim or encounter.

I would say the systematization of this process is twofold. One, it’s about the systems that capture and relay the data, that it’s built into the workflow in a systematic way so it’s always asked of members, no matter where they present for their healthcare. Two, as this data starts to get collected or reported systematically... how do we build standard processes or ways in which the needs that are identified then get referred out to community partners who can then meet those needs and for there to be a bidirectional loop.”

– State of Hawaii, Department of Health and Human Services, Med-QUEST Division

States and MCO interviewees noted a need for more resources, investment, and time for establishing and synchronizing data systems.

State interviewees spoke of a need for more systematic collection, sharing, and use of these data, which requires enhanced resources to develop infrastructure to support a single system or platform. Enhancing infrastructure capacity requires funding. Funding can help states and MCOs establish a robust infrastructure to support technological capacity (servers, storage), workforce (staff), and other resources (investment dollars to establish systems or harmonize across existing siloed systems). In addition, funding helps engage communities in health equity initiatives and provide supports to communities experiencing inequities.

“There can be a culture that identifying an issue brings more work. Even if you get to a point where you can identify things, do you then have the bandwidth or capacity to follow up on that? As a state agency, we have our own requirements for accessing data, contracting from new data sources, bringing those in, housing them, the responsibilities for all of that, which can be huge bodies of work. So even when we recognize that there is something that can support some of that work, we may not have the manpower to do it or we may not have the resources to bring in any additional data”

– Washington Health Care Authority

Using delivery system levers improves state, MCO, and provider accountability for improving data collection to advance health equity

States use managed care contracts to drive more equitable outcomes and encourage provider accountability towards reporting progress in reducing inequities in outcomes.

Some states require MCOs to submit data on race, ethnicity, and HRSN. 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 interviewees and MCOs. A combination of state and MCO health equity goals for priority populations guide measure selection for stratification. Some select specific subsets based on priority areas while others take a broader approach to stratify globally across measure sets. Most stratified measures focus on clinical and utilization domains with evidence of disparities, including child and maternal health, chronic conditions, and access to care. In addition to race and ethnicity data, a few interviewees shared that they are or plan to expand collection efforts to capture disability and SOGI.

Potential Changes to CMS Core Measures

When final, [CMS core measures](#) regulation could require states to stratify some child and adult behavioral health measures by demographic data.

MCO Requirements for Race and Ethnicity Data Collection

[Sixteen of 45 states](#) reported that they require MCOs and other contractors to collect race and ethnicity data in Kaiser Family Foundation’s annual budget survey.

“Now how do we take the places where we are measuring, where some of those disparities exist, and apply incentives for strategies to actually act on them and do something other than just the measurement and reporting of it... Sometimes that’s harder to have a cohesive strategy around.”

– Minnesota Department of Human Services

“There’s different ways in which you can [hold plans accountable]. You can go and talk to them. You can give them corrective action plans. You can impose sanctions, if it is something that is a sanctionable activity... because we’re seeing where sometimes just the corrective action plan is not enough to move the needle. Our intent here is to hold people accountable because we are entrusted for the care of the 1 in 3 Californians that we have a responsibility for. I don’t think it’s any one thing that we’re doing; it’s a combination of things.”

– California Department of Health Care Services

Over half of states require MCOs to maintain National Committee for Quality Assurance (NCQA) Health Plan Accreditation to standardize data quality; a few require Health Equity Accreditation.¹⁰ To place more emphasis on health equity advancement, NCQA launched the Health Equity Accreditation program in fall 2021. Some states view the new Health Equity Accreditation as a more robust accreditation framework that ties race and ethnicity data collection with HRSN needs and community partnership. A few are yet to include the requirement in MCO contracts as they are waiting to see how the new program progresses.

State and MCO Highlights

- **Community Care Plan** and **Neighborhood Health Plan of Rhode Island** are upgrading their case management systems and data infrastructures to better prepare them to meet standards when they pursue Health Equity Accreditation.
- **South Carolina** now requires contracted MCOs to obtain Health Equity Accreditation. They view the accreditation as way to set standards around fundamental race and ethnicity data capabilities to advance health equity.

Several states and MCOs highlighted the importance of routine monitoring with a focus on collaboration and regular communication to promote accountability. They described meeting routinely with MCOs and providers to review progress on measures, understand challenges and needs, and provide them with support on their data collection efforts.

State and MCO Highlights

- California’s **Health Plan of San Joaquin** holds joint operation’s committee meetings with local hospitals and large medical groups that serve their members to focus on identified disparities and targeted interventions.
- **Michigan** and **Pennsylvania** hold mandatory quarterly quality review meetings with their health plans to have robust discussions to review progress on select quality measures and progress being made to close targeted disparity gaps.

States also use payment models, quality withholds, and other incentives to encourage improved quality of health equity data collection and reporting.

States use an array of financial arrangements to drive quality of care and data collection, including P4P and quality withholds. This includes P4P programs and incentivizing hospitals and ACOs to improve

State Delivery System Levers to Promote Health Equity Efforts

[Twelve of 44 states](#) reported that they have at least one financial incentive using capitation withholds, pay for performance, or state-directed payments for health equity-related quality measures in Kaiser Family Foundations annual budget survey. Ten of 37 states require MCOs to meet health equity reporting requirements. CMS also requires that states measure the impact of approved section 1115 waiver changes on disparities in access, quality, and health outcomes.

race and ethnicity data collection and meet certain quality targets tied to health equity goals. States also use quality withholds. Quality withholds are a type of risk arrangement between a state Medicaid agency and an MCO where the state withholds a portion of the MCO’s capitation payment and pays it back at the end of a performance period based on the MCO meeting specified performance targets.¹¹ Most states noted that they require MCOs to meet performance benchmarks and show improvement on select measures identified for health equity related goals.

State Highlights

- **MassHealth**, through its approved MassHealth Section 1115 demonstration waiver,¹² will financially incentivize ACOs and ACO-participating hospitals to provide complete data on REALD and SOGI, starting in FY 2023.
- **Michigan** plans to direct MCOs to carry out a P4P program to incentivize providers to meet certain thresholds and close disparity gaps. The provider’s P4P measures would mirror the P4P measures required of the MCOs. Beyond this minimum requirement, MCOs would have discretion to administer the incentive however they see fit. Michigan’s health plan quality withhold program assesses statistically significant improvement in the rate of disparity between Black and White enrollees across certain HEDIS measures. Michigan also has a standard for disparities experienced by Hispanic/Latinx populations. If a plan does not perform well enough, they lose withhold amounts, which is in turn shared across plans that meet withhold targets.
- **Oregon** is exploring ways to use hospital, provider, and CCOs payments to leverage their capacity to collect and report REALD and SOGI data back to the state. They also developed a home-grown health equity measure that it ties to health plan incentives.
- **Pennsylvania** is implementing a new hospital quality incentive program for racial health disparities that will financially reward hospitals based on performance in comparison to benchmarks at the 25th and 50th percentile and self-year-over-year performance improvement on closing Black-white and Hispanic-non-Hispanic health disparities. The program will use Agency for Healthcare Research and Quality (AHRQ) software that incorporates more socio demographics beyond race and ethnicity to determine potentially preventable admissions. Hospitals may earn full, partial or no payout for each based on their performance.

“We are undertaking a paid for data completeness program as part of our overall waiver. And all of this goes back to that fundamental goal of being better able to understand where there are disparities, and then to be able to financially incentivize the reduction of disparities for our members across various departments.”

–MassHealth

Some states are exploring ways to directly incentivize providers and MCOs to conduct HRSN screening and collect HRSN data. One approach states are using to move providers and MCOs toward greater HRSN data collection or social risk factor screenings is to link associated activities and processes to incentives or reimbursement.

State and MCO Highlights

- Florida's **Community Care Plan** plans to incentivize certain providers to use Z codes as part of its P4P section of the contract in the upcoming year.
- **MassHealth** created its own HRSN screening measure. For its Section 1115 demonstration, the state collects data on food and housing insecurity at the enrollee level. The state adjusts capitated rates to ACOs for social risk, including homelessness status captured via Z code or by the presence of three or more addresses in the state's administrative record for an enrollee within a year. Use of Z codes has increased since the use of these capitated rates. In the future, the state hopes to tie hospital performance on these measures to hospital-level incentives to reduce disparities.
- **Tennessee** providers participating in Health Starts Provider Partnerships are required to use Z codes to track enrollees' social needs. The provider initiative focuses on payment models to integrate HRSN into systems of care and report findings back with the community and partners to closed-loop referral process.

Sharing data publicly and with providers helps hold states, MCOs, and providers accountable for collecting data to decrease gaps in health disparities

Some states release public facing health equity reports and data dashboards while others share data back with MCOs and providers. These data dashboards exist at both an aggregate level and at more granular levels. These interactive dashboards may include enrollee-level data linked across systems (e.g., nutrition, labor, education, child welfare, development services, family services) or may show disaggregated data by racial or ethnic groups. Some states work with their state HIE, APCD, or other third-party vendors to provide these dashboards. Interviewees noted these dashboards and public facing reports provide a level of accountability for MCOs, providers, and for the state Medicaid department itself. Some states that do not have this type of shared data warehouse or dashboard available noted their interest in such mechanisms. However, a few noted that while the public facing dashboards and reports are useful for accountability, they have some concerns about data quality and the data sources that inform these reports. States also share data back with MCOs and providers.

State and MCO Highlights

- **California** produces publicly available [health disparities reports](#) conducted by the External Quality Review Organization (EQRO) using the managed care accountability set ([MCAS](#)) measures reported by 25 Medi-Cal MCOs.
- **Florida** has a smart alert system that parses health plan data specific to certain quality measures such as food insecurity, transportation, or housing needs. Florida’s **Community Care Plan** created an internal dashboard that breaks out their data by race and ethnicity, gender identity, and ZIP code.
- **MassHealth** and **Oregon** are actively working to establish data sharing agreements and develop dashboards to share data back to ACOs, providers, and CCOs.
- **Minnesota** releases [public-facing, annual legislative reports](#) on the Eliminating Health Disparities Initiatives.
- **Pennsylvania** makes information available on their department website, including HEAT/health equity maps that provide the public and providers with an understanding of different health and HRSN outcomes by communities and by race and ethnicity.
- **Washington** has several public-facing dashboards, including a [Healthier Washington Dashboard](#), a maternal and child health dashboard, an emergency department utilization dashboard, and a dashboard specific to Apple Health (Medicaid) client eligibility stratified by race and ethnicity.

“When we start showing data and sharing data and showing the managed care plans what their outcomes are in general, and then being able to disaggregate that to say, ‘Well, here’s what it looks like for your consumers who identify as Black, consumers who identify as Hispanic.’ And just that sort of transparency and the fact that they have to interact with the department and explain why is it that they’re getting four outcomes let’s say in prenatal care for a certain population, it makes them accountable because you can’t question data. They could say the data is wrong, but most likely they usually don’t because it’s their data. They then know they need to do something about it.”

– Pennsylvania Department of Human Services

Engaging state leadership and community members garners buy-in for health equity data collection efforts

Competing priorities and provider and enrollee resistance can pose challenges for advancing health equity data collection efforts.

Competing or evolving priorities can make it difficult for states and providers to keep health equity data collection efforts at the forefront. Interviewees noted that health equity is a

multifaceted problem and long-term work that does not always align with the needs or demands of political cycles or public funding. State interviewees also noted that prioritizing health equity initiatives is a challenge because current analyses point to challenges in many different areas and at many different levels (i.e., individual, institutional, structural). As one interviewee notes, *“the size and scope of the problem”* is very large. Thus, interviewees noted that with finite time, resources, and capacity, states need a cohesive strategy for applying data to inform health equity program and policymaking and establishing priorities.

“We early on realized if we spend most of our attention on data, that’s not going to cut it. We’ve known for decades that there are health inequities. If we just say we’ll focus on data, it will be another 10, 20 years from now and our data will be a little bit better, but our health equity might not be... So, yes, we’re doing a lot to improve our data, but we need to be doing more than just focusing on data... we know that there are disparities.”

–MassHealth

“Prioritization within the world of health equity has been tricky because even if you’re using the data to guide you, the data will tell you that there’s challenges in lots of different areas. For our clinical, program, and policy folks, funding and staff time is not infinite. We are committed to advancing health equity, even when there are limited resources. State agency folks do great work, but oftentimes their plates are pretty high.”

– Washington Health Care Authority

Without leadership buy-in and support, some state interviewees noted they have faced resistance when engaging providers in data collection efforts. For example, interviewees described facing resistance from providers who note they do not know how to collect requested data or who have limited capacity and infrastructure to make data systems changes. Providers and MCOs may be resistant to changing how they collect and report data due to the burden of reporting information differently to multiple entities to meet state and federal requirements that do not always align. Interviewees noted that adding or altering data collection tools can create additional administrative work at both the provider level (in collecting or managing patient data) and the state level (in coordinating resources to ensure the data are usable across state programs). A few interviewees noted they have technical assistance meetings with providers to teach them how to enter data, remind them to input Z codes, and share findings from data.

“The problem of different reporting standards—it looks like while Oregon is ahead, leading in this effort to collect REALD [Race, Ethnicity, Language, and Disability] and SOGI [Sexual Orientation and Gender Identify] data and use, we always bump against existing federal standards. So providers have to 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. That creates some resistance in wanting to do what we are asking of them to do.”

– Oregon Department of Human Services

“Data collection often drives client administrative burden—more forms to fill out, repeating information, etc.—and we have to ensure that we’re collecting the right data in a way that doesn’t put more unnecessary burden of paperwork on our clients. Then we must make sure it is actionable, that we use the data to improve health outcomes.”

– Washington Health Care Authority

A few state interviewees mentioned specific challenges around how Medicaid enrollees and providers perceive collection of HRSN data. Interviewees noted enrollee concerns about how the state or their provider would use HRSN data. For example, interviewees noted that enrollees are concerned that reporting food insecurity or housing needs could put them at risk for child welfare interventions due to mandatory reporting. In addition, interviewees noted provider concerns that collecting HRSN data can lead to liability fears. For example, if providers do not have adequate resources or referral networks to support their patients once they identify a social need via screening, particularly with sensitive issues like domestic violence and homelessness. Therefore, providers may feel it is negligent to ask about these needs without having the ability to resolve them.

“One that came to light in the State Innovation Model was, in particular, asking about potential domestic violence. If there is not a resource available and that’s documented in a provider’s EHR, there’s significant liability to that provider for not providing some sort of connection or resource. There was hesitancy to engage in that work.”

– Michigan Department of Health and Human Services

Another point of provider concern or hesitancy is the inclusion of non-medical providers, who are important to providing appropriate and culturally responsive care (particularly community health workers and translators for people with limited English proficiency). Providers expressed concern that their presence may introduce hesitancy among patients concerned about how these providers will use or interpret their personal information and data (since they are not their doctors). An interviewee highlighted there are still broader questions related to race, ethnicity, and HRSN data around how much falls under the responsibility of the state Medicaid agency and of MCOs to address an individual’s HRSN when there are other benefit programs and agencies that are also address these issues.

State leadership and community engagement promotes a culture of health equity within and across agencies, including helping increasing provider buy-in for efforts.

Having state executive leadership that promote systemic health equity efforts is critical for buy-in across staff, including promoting provider buy-in. Interviewees noted that finding incentives or levers to drive change at the state level and within organizations can be a challenge. One interviewee described this as “*systems transformation work*” that requires political will and intentionality to support collecting these data. While approaches like value-based payment help, they require a lot of support and buy-in to be effective. States stressed the important roles of governors, legislatures, and executive level state agency staff in setting a clear strategy and vision for health equity. In some states, having political will and leadership buy-in from state legislatures and governors who issued directives and policies laid the groundwork for systemic changes. They were also key in promoting buy-in for collection of data to advance health equity, including data around race and ethnicity.

States also emphasized the importance of having an agency champion to prioritize health equity not just externally but also within the agency. This includes champions within and across state agencies and preferably at the highest executive level. Champions can help overcome challenges, promote political buy-in, and develop and implement legislative mandates to advance goals and create and ensure sustainable support.

State Highlights

- In **Florida**, the Medicaid Chief Medical Officer took on the health equity charge to ensure they did not lose momentum and could maintain inter-agency collaborations throughout the COVID-19 pandemic, which had brought about unexpected obstacles including prioritizing pandemic response activities. Most recently, the 2022 Florida legislature passed House Bill 855.¹³ Beginning in calendar year 2026, the new law requires each Medicaid MCO to stratify and publicly report performance measure data by age and REALD (as determined by the Social Security Administration). The new law also requires MCOs to collect and report on an expanded set of performance measures including the Adult and Child Core Measure sets. These are national key indicators of access to, and quality of, health care received by Medicaid beneficiaries.
- The **Oregon** legislature passed a law that requires healthcare providers to collect REALD information for healthcare encounters related to COVID-19 and share this information with the Oregon Health Authority. This was a dramatic change for providers, but the state set up comma-separated values (CSV) spec files for providers to send data weekly, which ultimately opened new pathways for other data collection.
- **Washington** established a new state agency to guide policy, programs, and data around health equity. In 2020, the governor and Racial Justice Council leveraged political will to require all providers to submit REALD data for all COVID-19 encounters.

“We wanted to, as we work to refine our approach to data collection, invite our colleagues around the state to weigh in on how we should all be doing it to minimize patient, family burden, payor, and provider burden, to really get us all aligned around one common approach. The task force is a voluntary standard setting body in the sense that members, individuals, or organizations do not have to adhere to the recommendations. But we have very good voluntary alignment with the quality standards currently. So we expect that, with such an engaged health care sector, this will be no different in future years.”

– MassHealth

States and MCOs highlighted the role of community engagement in improving data quality.

State interviewees discussed that tools and systems to collect, refer, and track HRSN data must be informed by how they are being used by providers or community-based organizations. They also described a need to engage community members to understand how they categorize their identities and engage them in updating racial and ethnic categories. A few MCOs have meetings with their members to address the barriers members face in their communities.

State and MCO Highlights

- The State of **Hawaii** Department of Health and Human Services, Med-QUEST Division is committed to meeting standards for linguistically and culturally appropriate services, partnering with community-based organizations who are made up of people who have those linguistic and cultural backgrounds, helping their enrollees with getting access to coverage (whether on Medicaid or the Marketplace), and offering other state-funding programs.
- **Health Plan of San Joaquin** has a “community affairs committee” composed of plan staff and local community members who meet to bi-directionally share information and feedback on community-level interventions. Also, the plan is increasingly meeting with community-based organizations, local housing authorities and local police departments to discuss interventions and ways to support people at-risk for incarceration.
- **MassHealth** leveraged a technical advisory board, issued a request for information, and worked with an external organization to conduct focus groups with consumers to better understand how to design data collection tool questions and more effectively collect data.
- **Michigan** has the Community Health Innovation Regions, a social care model designed to have “community conversations” about what the data are showing for enrollees’ communities and to better understand enrollees’ social needs.
- **Minnesota** is funding programs with strong community engagement components to better meet the community’s needs and be more responsive to communities they serve, particularly those who face structural racism and structural inequity.

Conclusion

States and MCOs have made substantial headway in thinking about the role of data collection in improving health equity. State Medicaid leaders increasingly recognize the importance of understanding the experiences and needs of enrollees with multifaceted and intersectional identities through revised race and ethnicity categories and other data collection mechanisms. States are working with other state agencies, MCOs, and providers to share data and aggregate data across multiple sources. They are also leveraging various delivery system levers like MCO contract requirements, pay for performance, and public dashboards to hold MCOs, providers, and ACOs accountable for progress towards advancing health equity. States are also working with leadership, champions, and community members to establish a culture of health equity and enhance their infrastructure to support data systems and processes. Nevertheless, federal guidelines for reporting REALD and SOGI, poor data quality, privacy concerns, lack of standardization, and competing priorities can make it difficult for states to collect the data they need to inform their health equity efforts.

Data are critical to advancing health equity in state Medicaid programs. Data provides state Medicaid programs and Medicaid MCOs with a more accurate depiction of the needs, health outcomes, and disparities their enrollees experience. Having federal guidance, technical assistance, and support on a more uniform strategy and standards to collect, analyze, interpret, and monitor REALD, HRSN, and SOGI data can ensure states and MCOs have the infrastructure, resources, and supports they need to continue to implement data efforts that promote health equity.

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