

State Medicaid Member Experience Quantitative Data Scan



The State Health Access Data Assistance Center (SHADAC), with support from the Robert Wood Johnson Foundation (RWJF), and in collaboration with partner organizations is in a second planning phase to assess whether a data tool to track indicators of health equity in state Medicaid programs can be designed, developed, and maintained to provide information and opportunities for structural change to improve health for people enrolled. At the end of the first project phase, a high-level conceptualization wireframe of a potential tool was developed. In this second planning phase, the project team will now create a series of resources to shed light on the opportunities and gaps in populating sections of a first iteration data tool that aligns with the wireframe created in phase one. Information in this specific resource is foundational for the section of the wireframe labeled “State Medicaid Member Experience.” This section of the tool (shown in green in the image below) would present state-level measures of member experience for various subgroups and how experiences are changing over time.

State Medicaid Member Experience			Health Outcomes			Underlying Factors
Measures describing how equitable a Medicaid member's journey is through the program at each stage.			Measures describing how equitable member health outcomes are.			Information about factors in the Medicaid system that perpetuate health inequities for people of color and other communities that have been historically marginalized and how they can be eliminated.
Seeking and Keeping Coverage	Satisfaction with Services and Providers		Mortality	Chronic Disease Prevalence	Clinical Quality Measures	
Accessing Needed Services	Member-reported Health and Well Being					
Medicaid Program Actions			Demographics			Root Causes (e.g., racism, ableism, classism)
Measures describing actions state Medicaid programs are taking to address health equity and what we know about what's working.			Measures describing who does/should Medicaid serve.			Vital Community Conditions (e.g., access to food, housing)
Program Structure	Coverage and Benefits	ACO/MCO Contracting and Provider Payment	Medicaid as Percent of Population	Medicaid Members	Medicaid Providers	Glossary of Terms
Community Engagement	Investments in Community Supports and SDOH	Medicaid Expenditures				Sources and Methods

Background

In May 2021, SHADAC embarked on a multi-phased project to assess the feasibility of developing a national Medicaid Equity Monitoring Tool that would be useful to state Medicaid programs, policymakers, advocates, and other organizations. The goal of this tool would be assisting with access to Medicaid and care, along with aiding efforts to advance health equity. Visit the SHADAC website for an [overview of the project](#).

Summary of Key Takeaways

- The State Health Access Data Assistance Center (SHADAC) with support from the Robert Wood Johnson Foundation (RWJF) finished the first phase of our Medicaid Health Equity Monitoring Tool project with the creation of a **high-level conceptual wireframe** of a potential tool.
- Phase two requires **identifying both opportunities and gaps in populating sections** of that wireframe. This resource focuses specifically on **Medicaid member experience measures**.
- We **identified 15 subpopulations of particular interest** to keep centered in equity work.
- **Five data sources** with the greatest potential for member experience measures were identified: BRFSS, NSCH, SIPP, PRAMS, and NCI-AD/NCI-IDD
- **Critical gaps in data sources** and data availability were identified. These include gaps in **adult experience/satisfaction measures, adult measures of discrimination, very limited Medicaid data** for American Indian/Alaskan Native, Asian/Pacific Islander, and birthing populations, and additional **measures for seeking/keeping coverage**.
- Researchers propose **three possible strategies for addressing these key gaps**: augment existing data collections efforts, expand use of Medicaid CAHPS survey, and conduct new data collection with targeted oversampling.

In the initial phase, SHADAC recruited an Advisory Committee of experts, including state Medicaid agency staff, policymakers, researchers, and representatives of marginalized communities that have an interest in tracking health equity in Medicaid. The project team also conducted key informant interviews to explore whether there is a need for an equity monitoring data tool. The Committee confirmed the need for a tool and agreed on a broad purpose: to serve as an accessible, flexible, member-centered data resource that allows users to monitor health equity-related activities and outcomes and hold Medicaid accountable for actionable solutions that improve access to care and advance equity, health, and well-being in communities.

Measurement concepts that consistently rose to the top of the Advisory Committee’s priority list were those related to understanding the Medicaid member’s experience. The Advisory Committee was interested in assessing member experiences not only after they have received care, but also earlier in their journey through the Medicaid program related to seeking and enrolling in coverage and accessing services. This brief summarizes findings related to the data and measurement scan focused on member experience measures, highlights critical gaps, and proposes potential strategies for addressing these gaps.

Member Experience Measures Defined

Committee members urged consideration of measurement concepts including (but not limited to): member satisfaction, shared decision-making, and well-being. We found it helpful to take the feedback from the Advisory Committee on member experience and “bucket” potential measure concepts in to five high-level domains, which included **accessing services; experience/satisfaction; discrimination within the health care system; member reported health and well-being; and seeking and keeping coverage**. Table 1 below provides example measures under each domain.

Table 1: Example Member Experience Measures by Domain

Domain	Example Measures
Accessing Services	<ul style="list-style-type: none"> • Usual source of care • Difficulty accessing care - wait times, hours of operation, provider doesn’t accept coverage, etc. • Time between diagnosis and treatment
Experience/Satisfaction	<ul style="list-style-type: none"> • Member satisfaction • Provider rating • Shared decision making
Discrimination	<ul style="list-style-type: none"> • Unfair treatment due to race, ethnicity, gender identity, disability status • Provider showed respect for culture
Member Reported Health and Well-being	<ul style="list-style-type: none"> • Physical health status/well-being • Mental health status/well-being • Quality of life
Seeking and Keeping Coverage	<ul style="list-style-type: none"> • Churn • Experience with enrollment and renewal process • Availability and quality of navigator services

Source: SHADAC synthesis of Phase 1 Project Advisory Committee discussions, 2022

It is important to note that member experience measures in this context exclude a range of process and outcome measures that are commonly associated with evaluation and monitoring of the Medicaid program. For example, member experience measures do not encompass clinical quality or health outcomes such as morbidity and mortality. In addition, they do not include process measures associated with state Medicaid program actions to address equity in a member’s experience, such as application processing time, reenrollment,

disenrollment, or culturally and linguistically supportive services. These measures or measure concepts will be explored later in this Medicaid Equity Monitoring Tool project planning phase.

Measure Granularity

The Advisory Committee recommended focusing the Medicaid Equity Monitoring Tool on people who are “at the margins” in order to keep the perspective of the communities that are most marginalized and impacted by Medicaid program inequities at the center of this work. While the Committee had difficulty prioritizing target populations, they were able to identify 15 populations of interest:

- Black/African American people
- American Indian/Alaska Native people
- Hispanic people
- Asian/Pacific Islander people
- Non-English-speaking people
- People living in rural areas
- Adults (18-65) with very low income (under 50 percent Federal Poverty Level)
- Adults living with disabilities
- Dually eligible (Medicare and Medicaid) people
- Adults with mental illness and/or substance use disorder
- Justice-involved people
- Persons who identify as LGBTQ+
- Pregnant/birthing people
- Infants (0-1 years)
- Children (>1-18 years)

In order to focus efforts around a first-version tool, Committee members participated in a sorting exercise to help inform us on the direction to begin our data scan. The result of this exercise directed our focus on data and measurement that could shed light on the member experience for people of color (including Black/African American people, American Indian/Alaska Native people, Hispanic people, and Asian/Pacific Islander people), pregnant/birthing people, and people living with disabilities. Allowing users to consider intersectionality (the ways our multiple identities shape and compound to create certain experiences) is also a part of planning for the tool, i.e., information on pregnant/birthing people who also have a mental illness or substance use disorder, or people living with disabilities who are children.

Data Scan

With our focus on member experience measures and key subpopulations as framing, we cast a broad net for potential sources to include in our scan. This included survey, administrative, and vital statistics data, along with some curated data (such as the [Medicaid and CHIP State Scorecard](#)) as possible sources.

We then evaluated each potential source in terms of its ability to provide relevant measures within each domain, and support estimates at different levels of granularity. Specifically, we looked at whether data sources could support estimates at the state, state-Medicaid, and state-Medicaid-subgroup (e.g., Black, American Indian, Asian, Hispanic, pregnant/birthing, disabled) level. It was also critical that the data be timely and collected on an ongoing basis to allow for examining trends over time. ***Our goal was to narrow in on sources that supported estimates of member experience measures for at least some states at the state-Medicaid-subgroup level with data that allowed for public reporting.*** Table 2 below summarizes our findings.

Based on this initial review, we identified sources that seemed to have the greatest potential for populating a first version of the Medicaid Equity Monitoring tool. These included:

- Behavioral Risk Factor Surveillance System (BRFSS)
- National Survey of Children’s Health (NSCH)
- Survey on Income and Program Participation (SIPP)
- Pregnancy Risk Assessment Monitoring System (PRAMS)
- National Core Indicator-Adults with Disabilities (NCI-AD) and the National Core Indicator-Adults with Intellectual or Developmental Disabilities (NCI-ID)

Each of these sources support measurement for some states at the state-Medicaid-subgroup level, are fielded regularly, and contain measures related to member experience.

Some data sources had considerable potential in terms of content and granularity but were ultimately eliminated from our detailed review for reasons of accessibility or timing. For example, as demonstrated in Table 2, the Medicaid CAHPS surveys contain information across member experience domains, but the data cannot be used for public reporting. The Nationwide Adult Medicaid Consumer Assessment of Healthcare Providers and Systems (NAM CAHPS) also contains considerable information of interest, but it has not been fielded since 2014.

It is also important to note that Transformed Medicaid Statistical Information System (T-MSIS) has the potential to produce measures related to timely treatment that are not available elsewhere. However, given the considerable cost and time associated with analyzing this data set, along with findings that suggest [its data on race/ethnicity is of poor quality in many states](#), we did not include it for detailed review for the first-version tool on member experience. While not suited for member experience measures for the first iteration of this tool, this data may be an important source in future iterations or for other measure domains.

Table 2: Potential Data Sources to Support Member Experience Measures for a Medicaid Equity Monitoring Tool

Data Source	State	State-Medicaid	State-Medicaid subgroup (e.g., disability, race/ethnicity)	Accessing services	Experience/satisfaction	Discrimination	Health/Well-Being	Seeking and keeping coverage
American Community Survey (ACS)	X	X	X					
Behavioral Risk Factor Surveillance System (BRFSS)	X	X	Some	X			X	
Consumer Survey of Health Care Access – AAMC	X	Some	Very Limited	X	X	X		
Current Population Survey-Annual Social and Economic Supplement (CPS-ASEC)	X	X - Pool 2 years	Some				X	
Household Pulse Survey (HPS)	X	Some - pool weeks	Very Limited				X	
Medical Expenditure Panel Survey-Household Component (MEPS-HC)	10 largest			X	X		X	
Medicaid State Scorecard	X -Varies by measure	X -Varies by measure		X	X			
National Core Indicator-Intellectual and Developmental Disabilities (NCI-ID) In Person Survey	X	X	Some	X	X	X	X	
National Core Indicator-Aging and Disabilities (NCI-AD)	X	X	Some	X	X	X	X	
National Health Interview Survey (NHIS)	X - Pool 2 years	Some	Very Limited	X	X	2017 only	X	
National Immunization Surveys (NIS)	X							
National Survey of Children's Health (NSCH)	X	X - Pool 2 years	Some	X	X	X	X	X
National Survey on Drug Use and Health (NSDUH)	X	Very Limited		X			X	
National Transgender Survey	X	Some	Very Limited	X	X	X	X	
Pregnancy Risk Assessment Monitoring System (PRAMS)	X	X	Some				X	
Survey on Income and Program Participation (SIPP)	X	X	X				X	X
Transformed Medicaid Statistical Information System (T-MSIS)	X	X	Some	X				X

Data Source	State	State-Medicaid	State-Medicaid subgroup (e.g., disability, race/ethnicity)	Accessing services	Experience/satisfaction	Discrimination	Health/Well-Being	Seeking and keeping coverage
CDC WONDER Natality Data	X	X	X					
Youth Risk Behavior Surveillance System (YRBSS)	X						X	
No State Estimates								
Medicare Current Beneficiary Survey (MCBS)				X			X	
National Survey of Family Growth (NSFG)				X			X	
Health and Retirement Survey (HRS)				X	X		X	
National Health and Nutrition Examination Survey (NHANES)				X			X	
Outdated Data (last update 2014 or earlier)								
SEER-Medicaid	X	Some	Some	X				
Nationwide Adult Medicaid Consumer Assessment of Healthcare Providers and Systems (NAM CAHPS)	X	X	Some	X	X		X	
No Public Reporting Allowed								
CAHPS Health Plan Survey Database-Adult Medicaid Survey	X	X	Unknown	X	X		X	
CAHPS Health Plan Survey Database-Child Medicaid Survey	X	X	Unknown	X	X		X	

Source: SHADAC review of federal surveys.

Available Measures by Domain and State for Subpopulations of Interest

We conducted in-depth reviews of the data sources discussed above that held most promise for supporting member experience measures in a first iteration tool. Table 3 below summarizes the number of measures available in each domain for the BRFSS (which covers adults), the NSCH (which covers children), the SIPP (which covers the whole population), and PRAMS (which is relevant for birthing people).

Table 3: Number of Measures in Promising Sources about Member Experience, by Measure Domain

Measure Domain	BRFSS (adults)	NSCH (children)	SIPP (adults & children)	PRAMS (birthing)
Accessing Services	2	9	0	0
Member Reported Health and Well-Being	3	2	1	1
Experience/Satisfaction	0	12	0	0
Discrimination	0	1	0	0
Seeking/Keeping Coverage	1	3	1	0

Source: SHADAC review of federal surveys. Most recent years of data available at the time of review were: BRFSS (2021), NSCH (2020-2021), SIPP (2021), and PRAMS (2021).

In addition to the number of measures available by measure domain, we also wanted to gain an understanding of how many states would have sufficient sample to support estimates for our key subpopulations of interest. We were able to conduct preliminary sample size checks with the BRFSS and NSCH. These results are summarized below. As shown, there are very few states with sufficient sample in either data source to support estimates for the American Indian/Alaskan Native, Asian/Pacific Islander, and birthing populations; there is better representation for Black/African American and Hispanic/Latinos across states. Both data sources support estimates for those with disabilities in all fifty states and D.C.

Table 4: Number of States Supporting Estimates for Subpopulations of Interest within Medicaid* in Promising Data Sources

Subpopulation (within Medicaid)	BRFSS (adults)	NSCH (children)
Black/African American	32	21
American Indian/Alaskan Native	9	1
Asian/Pacific Islander	4	5
Hispanic/Latino	30	33
Birthing+	3	N/A
People with Disabilities	51	51

*States and D.C. were considered to have sufficient sample if combining two years of data provided at least 50 cases.

+PRAMS data could provide information for health status among the birthing population, but we were not able to conduct sample checks with this data source.

Source: SHADAC review of federal surveys. Most recent years of data available at the time of review were: BRFSS (2021), NSCH (2020-2021), SIPP (2021), and PRAMS (2021).

Additional Data for People with Disabilities in Medicaid

The NSCH and BRFSS have considerable power to produce estimates at the state-Medicaid-people with disabilities level. In addition to these broad, population-based surveys, some states also collect information about persons with disabilities in Medicaid through two focused surveys: the NCI-AD that focuses on those with physical disabilities, and the NCI-IDD that focuses on those with intellectual and developmental disabilities. We were interested in the extent to which these data sources would enable measurement of persons with disabilities in a more intersectional way, for example by race/ethnicity, within states. Table 5 below summarizes the number of states in each data set that could potentially support these estimates.

Table 5: Number of States Supporting Estimates for Subpopulations of Interest* in National Core Indicator Data

Subpopulation	Physical Disabilities	Intellectual and Developmental Disabilities
Black/African American	14	21
American Indian/Alaskan Native	1	0
Asian/Pacific Islander	3	1
Hispanic/Latino	5	4

*States were considered to have sufficient sample to support estimates if there were at least 50 cases in the 2017-2018 data.

Source: SHADAC review of National Core Indicator data.

The NCI data sets have potential to support estimates for Black/African American people with disabilities in many states, but far fewer states have data available for Asian/Pacific Islander, Hispanic/Latino, and American Indian/Alaskan Native people with disabilities.

The data also have important limitations to consider. Firstly, if these data were to be used for a first-version tool, permission would need to be obtained for each state participating in the survey. Something else to consider is that the NCI-IDD data are not free; obtaining the data costs approximately \$12,000. The content and sample can also change from one timeframe to the next, depending on each state's priorities. Finally, not all states participate in these surveys, and some participate irregularly. For example, only fifteen states collected data for the NCI-AD survey in the 2017-2018 survey, while 35 participated in the NCI-IDD survey.

Key Gaps and Potential Strategies to Address Them

As the review above demonstrates, there are critical gaps in the availability of data to monitor member experience in a first-version Medicaid Equity Monitoring Tool. The key gaps we have identified include:

- Measures for adults related to experience/satisfaction
- Measures for adults related to discrimination
- Very limited data to support state-level estimates of American Indian/Alaskan Native, Asian/Pacific Islander, and birthing populations within Medicaid
- Only one measure (churn) in the domain of seeking/keeping coverage

After identifying these key gaps, we are considering three high-level approaches to addressing these data gaps:

Augment Existing Data Collection Efforts

One strategy for addressing data gaps to measure member experience would be to augment existing data collection efforts. Because this method would be building on already available infrastructure, it may be more cost effective than undertaking entirely new data collection. These strategies also rely on augmenting data sources that are population-based, rather than targeting only the Medicaid population, which has the advantage of providing benchmarks to people with other coverage types.

Based on our review, two specific potential strategies to improve data availability for adult populations include:

- Adding the **discrimination module from NHIS**, fielded by the National Center for Health Statistics (NCHS), back to regular rotating content, with **oversampling to support estimates of key subpopulations within Medicaid** in all states. This survey has a range of content that could be used for a first-version equity tool, so this approach also has the potential to expand and streamline data sources for the tool more broadly.

- Expanding the sample of the **Consumer Survey of Health Care Access** fielded by the Association of American Medical Colleges (AAMC) to support subpopulation estimates within Medicaid at the state level. This survey has a broad range of content relevant to understanding Medicaid member experience but has limited sample. This survey also has existing questions related to unfair treatment due to race, culture, ethnicity, and sexual orientation, so there is potential to address the critical data gap related to understanding member experiences with discrimination in the health care system as well. However, based on our preliminary sample checks, the sample would need to expand by a larger magnitude compared to the NHIS in order to support estimates at the state-Medicaid-subgroup level. The data are also less well-documented than the NHIS; preliminary work suggests that there may be data quality issues that would need to be addressed as well.

Expand Allowed Use of Medicaid CAHPS

The Medicaid CAHPS data are designed to capture information about member experience, but the data [cannot be used for public reporting](#). Allowing use of these data for public reporting would address key data gaps in experience/satisfaction measures for adults. There has also been discussion of adding questions related to discrimination to the CAHPS, which would also address that key gap. However, issues with representativeness (the survey is only fielded with managed care organizations and [research data files](#) only include those that agree to share their data) and sufficiency of sample to support estimates for key subpopulations would still need to be explored and addressed.

New Data Collection with Targeted Oversampling

The NAM CAHPS that was fielded by Centers for Medicare and Medicaid Services (CMS) once in 2014 would, if fielded again on a regular basis, address the experience/satisfaction data gap for adults in Medicaid. Like the CAHPS, there would also be potential to add a module to NAM CAHPS that collects information about discrimination and cultural competency. It may also be possible to add questions related to Medicaid members' experiences with the enrollment and renewal processes, which would expand the scope of measures related to seeking and keeping coverage, addressing another one of the identified gaps. There is potential for this survey to also address data gaps for American Indian/Alaskan Natives, Asian/Pacific Islanders, and birthing populations, as well, via targeted oversampling.

One advantage of this NAM CAHPS approach over the Medicaid CAHPS strategy is that the NAM CAHPS fielded in 2014 included the fee-for-service and managed care population, while the ongoing Medicaid CAHPS surveys are only relevant for those in certain managed care programs that agree to participate and share their data. Fielding another NAM CAHPS on an ongoing basis has been [recommended by MACPAC](#). However, obtaining the permission and funds for this data collection effort would require Congressional action, so it may be the most challenging approach of the ones proposed here to addressing data gaps in the near term.

About the Robert Wood Johnson Foundation

The Robert Wood Johnson Foundation (RWJF) is committed to improving health and health equity in the United States. In partnership with others, we are working to develop a Culture of Health rooted in equity that provides every individual with a fair and just opportunity to thrive, no matter who they are, where they live, or how much money they have.

Health is more than an absence of disease. It is a state of physical, mental, and emotional wellbeing. It reflects what takes place in our communities, where we live and work, where our children learn and play, and where we gather to worship. That is why RWJF focuses on identifying, illuminating, and addressing the barriers to health caused by structural racism and other forms of discrimination, including sexism, ableism, and prejudice based on sexual orientation.

We utilize evidence to advance health equity. We cultivate leaders who work individually and collectively across sectors to address health equity. We promote policies, practices, and systems-change to dismantle the structural barriers to wellbeing created by racism. And we work to amplify voices to shift national conversations and attitudes about health and health equity.

Through our efforts alongside the efforts of others, we will continue to strive toward a Culture of Health that benefits all. It is our legacy, it is our calling, and it is our honor.

For more information, visit www.rwjf.org.

About SHADAC

This resource was prepared by SHADAC Senior Research Fellow Lacey Hartman, MPP. State Health Access Data Assistance Center (SHADAC) is an independent, multi-disciplinary health policy research center housed in the School of Public Health at the University of Minnesota with a focus on state policy. SHADAC produces rigorous, policy-driven analyses and translates its complex research findings into actionable information for states.

For more information, visit www.shadac.org.

About the Medicaid Equity Monitoring Tool Project

The Medicaid Equity Monitoring Project is a multi-phased effort to explore whether a new national data tool could increase accountability for making actualized progress toward improving population health while also supporting state Medicaid programs in advancing health equity. The Robert Wood Johnson Foundation (RWJF) contracted with the State Health Access Data Assistance Center (SHADAC) and its subcontractor RACE for Equity to assess both tool need and feasibility. RWJF contracted with Health Leads to work collaboratively with the SHADAC team to engage community members in discussions of a potential monitoring tool. At the end of the current phase, SHADAC, RACE for Equity, and Health Leads will make recommendations about the feasibility of moving forward with designing and developing a Medicaid equity monitoring tool.

Resources developed throughout the multi-year project are available here: <https://www.shadac.org/Medicaid-Equity-Monitoring-Tool>
