Chapter 1:

Medicaid Race and Ethnicity Data Collection and Reporting: Recommendations for Improvement

Medicaid Race and Ethnicity Data Collection and Reporting: Recommendations for Improvement

Recommendations

1.1 The Secretary of the U.S. Department of Health and Human Services (HHS) should update the model single, streamlined application to include updated questions to gather race and ethnicity data. These questions should be developed using evidence-based approaches for collecting complete and accurate data. The updated application should include information about the purpose of the questions so that the applicant understands how this information may be used. HHS should also direct the Centers for Medicare & Medicaid Services to update guidance on how to implement these changes on a Secretary-approved application.

1.2 The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services to develop model training materials to be shared with state and county eligibility workers, application assisters, and navigators to ensure applicants receive consistent information about the purpose of the race and ethnicity questions. The training materials should be developed with the input of states, beneficiaries, advocates, and application assisters and navigators, user tested prior to implementation, and adaptable to state and assister needs.

Key Points

- Racial and ethnic health disparities persist throughout the U.S. health care system, and improving the quality of race and ethnicity data is needed to measure disparities and develop and implement policies to promote health equity.

- All state Medicaid programs collect race and ethnicity information on their applications and, as required by the Centers for Medicare & Medicaid Services, report these data to the Transformed Medicaid Statistical Information System. The completeness and accuracy of these reported data vary by state.

- Many states have challenges gathering these data from applicants, which can affect data quality. Applicants may have concerns with responding to these questions because of lack of understanding about how the information may be used, fears of being denied coverage, and categories not aligning with how they self-identify.

- Updating the race and ethnicity questions on the HHS model single, streamlined application with evidence-based approaches for asking these questions and explaining their purpose may ease applicant concerns and lead to increased response rates and reporting of more complete and accurate data.

- Developing model training materials that include information about the purpose of the race and ethnicity questions provides application assisters with better tools for educating applicants and may lead to improved applicant understanding and trust in providing sensitive information.

CHAPTER 1: Medicaid Race and Ethnicity Data Collection and Reporting: Recommendations for Improvement

There is a need to set priorities for advancing health equity in Medicaid to ensure beneficiaries receive equitable access to services and improve health outcomes. Improving the quality of race and ethnicity data is one step in enabling the federal and state governments, researchers, and other stakeholders to identify and measure health disparities driven by race and ethnicity and develop and implement policies to promote health equity. The Commission's recent work has focused on the collection and reporting of data to the Transformed Medicaid Statistical Information System (T-MSIS), the only federal Medicaid data source for all beneficiaries that includes eligibility, demographics, service use, and spending information (MACPAC 2022a, 2021b).[1] In addition to race and ethnicity data, the Commission acknowledges a need for collecting other demographic data to understand and address health inequities experienced by beneficiaries marginalized based on age, sex, disability status, sexual orientation, gender identity, primary language, and geography and the intersection of these identities (MACPAC 2022a). The U.S. Department of Health and Human Services (HHS), the Centers for Medicare & Medicaid Services (CMS), and some states have long made commitments to address health disparities and advance health equity; however, disparities in health care access and outcomes persist, and advancing health equity should be an ongoing focus (CMS 2022a, HHS 2022a).

There are known racial and ethnic health disparities in Medicaid, but the data needed to assess them are limited by quality concerns, which can lead to an inaccurate and incomplete understanding of the health disparities driven by these factors (James et al. 2021a). Improving these data will support policymakers as they develop and evaluate policies to address health disparities and equity. For example,

all states collect race and ethnicity data on Medicaid applications for their own analytical purposes and to meet reporting requirements for T-MSIS; however, states have challenges with and vary in their success with collecting and reporting complete and accurate data. Multiple approaches are necessary for addressing these challenges and improving the quality of these data.

To examine the challenges in collecting and reporting race and ethnicity data and opportunities to address them, we analyzed the availability of T-MSIS race and ethnicity data and conducted a literature review and stakeholder interviews.[2] The literature review focused on the federal data collection requirements, their applicability to state Medicaid programs, and the usability of Medicaid race and ethnicity data. Similarly, the interviews addressed these topics and how state Medicaid programs collect race and ethnicity data and report them to T-MSIS. Further, the interviews focused on identifying challenges with collecting these data and how to improve their usability. We interviewed HHS, CMS, the Congressional Research Service, and state Medicaid officials; research experts; beneficiary advocates; and representatives of Medicaid managed care plans and application assister organizations.[3]

The findings from the literature review and stakeholder interviews identified several challenges with collecting and reporting complete and accurate race and ethnicity data and several potential approaches to improving these data. State Medicaid agencies can only require applicant information that is necessary for making an eligibility determination, so the race and ethnicity questions must be marked as optional (42 CFR 435.907). As a result, states sometimes have difficulty collecting this information. For example, individuals may hesitate to self-report due to concerns about how the information may be used. Additionally, individuals may not provide accurate responses if they do not understand the race and ethnicity questions or do not feel their identities are reflected by the available response options. Explaining the purpose of the questions and providing categories that are reflective of the population may help address some of the collection challenges. States also have difficulty reporting these data to CMS in part because of state eligibility system and Medicaid Management Information System (MMIS) design. For example, some eligibility systems and MMIS store these data

in different formats, leading to potential losses in completeness and accuracy during data transfers. CMS has provided states with technical instructions and ongoing technical assistance to identify state reporting issues, and these challenges are becoming less common.

Efforts to address disparities should not be delayed until all of the current data quality concerns are resolved. Although there will be some continuing challenges with the completeness and accuracy of the data, some states already have race and ethnicity data of sufficient quality, and there are multiple approaches that can support state efforts to improve the quality of these data. The Commission makes two recommendations to improve the collection of Medicaid race and ethnicity data:

1.1 The Secretary of the U.S. Department of Health and Human Services (HHS) should update the model single, streamlined application to include updated questions to gather race and ethnicity data. These questions should be developed using evidence-based approaches for collecting complete and accurate data. The updated application should include information about the purpose of the questions so that the applicant understands how this information may be used. HHS should also direct the Centers for Medicare & Medicaid Services to update guidance on how to implement these changes on a Secretary-approved application.

1.2 The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services to develop model training materials to be shared with state and county eligibility workers, application assisters, and navigators to ensure applicants receive consistent information about the purpose of the race and ethnicity questions. The training materials should be developed with the input of states, beneficiaries, advocates, and application assisters and navigators, user tested prior to implementation, and adaptable to state and assister needs.

This chapter begins by describing the need for high-quality data to understand and address health disparities. It then outlines the federal and state priorities for improving race and ethnicity data. The

chapter goes on to describe the federal standards for collecting race and ethnicity data, the state data collection and reporting processes, and the current quality of Medicaid race and ethnicity data. It also describes the challenges with collecting and reporting high-quality race and ethnicity data and approaches to improving their usability. The chapter concludes with the Commission's recommendations and its rationale.

Importance of High-Quality Data to Address Health Disparities

Racial and ethnic health disparities persist throughout the U.S. health care system, including in Medicaid and the State Children's Health Insurance Program (CHIP). More than 60 percent of Medicaid and CHIP beneficiaries identify as American Indian and Alaska Native, Asian American and Pacific Islander, Black, Hispanic, or multiracial, making measuring and addressing disparities in these programs particularly important (MACPAC 2022c, 2022d, and 2021a). Gaps in Medicaid race and ethnicity data quality should not necessarily prevent their use or efforts to address disparities; however, without high-quality, self-reported data across all states, CMS, states, researchers, and other stakeholders are limited in their ability to measure and monitor disparities. Similarly, these data are needed to examine efforts to address disparities in access to care, use of services, and health outcomes to evaluate their effectiveness in advancing health equity.

Historically, many types of demographic data, including race and ethnicity, have not been collected consistently or uniformly across federal and state programs. Although established federal standards for collecting race and ethnicity data exist, having multiple standards may make it challenging for those collecting these data to know which is most appropriate. Further, these data are difficult to collect and often incomplete, hindering the ability to monitor and address disparities (James et al. 2021a, 2021b; HHS 2011a; OMB 1997). Other demographic information, such as sexual orientation and gender identity and disability, do not have data collection and reporting standards that are used consistently across federal data collection efforts, which also limits the availability of high-quality data for these populations

(Equitable Data Working Group 2022, Ortman and Parker 2021). Collecting comparable data on multiple dimensions of identity is important for ensuring that these populations are accounted for when measuring inequities in access to care. More complete data also allow for the assessment of disparities at the intersection of multiple demographic groups, such as measuring access to care and health outcomes for people with disabilities by race and ethnicity (Rubin et al. 2018). As part of the Commission's ongoing health equity work, we will prioritize examining opportunities to improve the collection of other demographic data in our future work.

Federal and state-level data often have high rates of missing race and ethnicity data, which may lead to an inaccurate and incomplete understanding of health disparities (James et al. 2021b). Recent research demonstrates that individuals most likely to face health disparities because of their race and ethnicity are least likely to provide this information (Labgold et al. 2021; Sholle et al. 2019).[4] For example, one study found that those who identify as Black, Hispanic, and Asian American and Pacific Islander were more likely than white-identifying individuals to skip these questions (Dembosky et al. 2019). Furthermore, incomplete data for small populations, such as American Indian and Alaska Native populations, may produce insufficient samples for statistical analyses, so these populations are often not reported in health disparities research. Current federal reporting standards do not include detailed categories for race and ethnicity, which are needed to improve the identification of disparities among smaller subpopulations that may otherwise be masked when they are aggregated to a larger group (Chau and Chan 2021). For example, under Office of Management and Budget (OMB) standards, a person could self-identify as Hispanic but not a more specific Hispanic subgroup, such as Puerto Rican.

Federal priorities for improving race and ethnicity data quality

The collection and reporting of high-quality demographic data are priorities of the Biden Administration's Equity Executive Order (EOP 2021). The Equitable Data Working Group, established by the Equity Executive Order, recommended federal strategies to improve the collection and disaggregation of demographic data and leverage underused data sources to conduct meaningful analyses to better understand racial and ethnic disparities. The report identified many challenges with using race and ethnicity data. For example, the ability to conduct analyses on smaller subpopulations is limited due to inconsistent collection of more granular race and ethnicity categories across federal data collection efforts. This is particularly true when assessing the intersection of race and ethnicity with other identities and demographic groups, such as disability status and primary language (Equitable Data Working Group 2022, EOP 2021).

In response to the Equity Executive Order, CMS developed a framework, modeled after the Healthy People 2000 Framework, to achieve health equity and eliminate disparities. The framework outlines five priority areas: (1) expand the collection, reporting, and analysis of standardized data; (2) assess causes of disparities within CMS programs and address inequities in policies and operations to close gaps; (3) build capacity of health care organizations and the workforce to reduce health and health care disparities; (4) advance language access, health literacy, and the provision of culturally tailored services; and (5) increase all forms of accessibility to health care services and coverage (CMS 2022a).

CMS is considering many approaches to improve the quality and usability of Medicaid race and ethnicity data. These data are collected as part of the Medicaid application process, and CMS is working with states to address barriers to reporting these data to T-MSIS. However, states also have challenges with collecting complete and accurate information from all individuals who apply for Medicaid and CHIP, which limits the quality of the data reported to T-MSIS. Therefore, CMS is also exploring other approaches to augment these data by leveraging other federal and state-level data sources for internal analyses (Box 1-1). These additional approaches will supplement efforts to measure and address health disparities in Medicaid, but they will not be used to modify the race and ethnicity data available in T-MSIS (CMS 2021b).

State priorities

State Medicaid programs are prioritizing health equity, including improving the collection and reporting of race and ethnicity data. However, most states are still early in the development process, and these efforts have initially focused on establishing infrastructure to support the work. In some states, this includes designating a dedicated Medicaid health equity official or requiring managed care plans to identify a health equity officer or design health equity requirements (Akard 2022, MACPAC 2022a). For example, North Carolina recently released its State Health Improvement Plan, which sets priorities for reducing disparities in health outcomes that disproportionately affect historically marginalized populations (NCDHHS 2022).

In interviews, states shared that they use race and ethnicity data for program administration (e.g., targeted outreach to beneficiaries) and to measure health disparities. Some states have methods to disaggregate Medicaid eligibility race and ethnicity data, and others are supplementing these data with additional sources for analyses (Box 1-1). Some states use race and

---

BOX 1-1. Other Data Sources and Methodology to Increase Data Usability

Self-reported data are considered the best method for collecting information that reflects an individual's identity. However, given the difficulty in collecting these data, self-reported data may often be missing. To increase the usability of race and ethnicity administrative data for research purposes, federal and state agencies are exploring ways to supplement Transformed Medicaid Statistical Information System (T-MSIS) race and ethnicity data with external data sources and imputation methods. These additional data sources do not replace the Medicaid eligibility data or change the data that states submit to T-MSIS.

Most of these efforts are in the early stages of development and are primarily used for internal validation and analyses. As these techniques are developed, guidelines should be established around the appropriate use of alternative data sources and imputation for internal analyses.

Alternative data sources. States may incorporate alternative data sources to validate administrative data and conduct additional internal analyses. For example, one state reported stratifying state Consumer Assessment of Healthcare Providers and Systems data by race and ethnicity to study health disparities at the plan level. The state also uses provider-collected race and ethnicity data as a tool to better understand the accuracy of administrative data.

A number of states we interviewed have ongoing efforts to leverage existing relationships with other public agencies, health providers, and Medicaid managed care plans to collect additional beneficiary race and ethnicity data. For example, one state Medicaid agency receives additional individual-level race and ethnicity data from other state agencies, which are saved separately from the state eligibility system and Medicaid Management Information System. The state Medicaid program is also working to collect data from managed care organizations, accountable care organizations, and hospitals. With more complete data, the state aims to monitor and address statewide inequities.

Data imputation. To address missing race and ethnicity T-MSIS data, the U.S. Department of Health and Human Services, the Centers for Medicare & Medicaid Services (CMS), and several state Medicaid programs are developing methods to impute missing administrative data with assigned values for analytical purposes.

In June 2022, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) published a technical report on imputing race and ethnicity data for people on exchange plans (HHS 2022b). The imputation method is based on an individual's first name, surname, and geographic location. ASPE and CMS report efforts to develop a similar methodology for use with Medicaid administrative data.[5]

---

ethnicity data to develop targeted policies to reduce disparities in health outcomes related to chronic health conditions and to improve service delivery for Medicaid beneficiaries. For example, one interviewed state is analyzing the burden of various chronic illnesses across the Medicaid population, and the data are informing a new policy to ensure that individuals with sickle cell anemia, a disease that disproportionally affects Black individuals, have access to adequate services, medications, and treatments (Ojodu et al. 2014).

Race and Ethnicity Data Collection Standards and Guidance

Existing minimum federal standards for collecting race and ethnicity data are intended to ensure the collection and reporting of uniform and comparable data. OMB established federal minimum standards for collecting race and ethnicity data in federally sponsored data collection efforts, and HHS established more granular guidelines for collecting and reporting these data in HHS-sponsored national population health surveys (HHS 2011a, OMB 1997). However, because these standards do not directly apply to state Medicaid programs, state data collection and reporting processes may not always be consistent with those used in federal data collection efforts or in other states (Gilfoil 2022, James et al. 2021b).

Federal OMB minimum standards

First established in 1977, the OMB federal minimum standards for race and ethnicity were intended to promote the comparability of data across all federal data collection and reporting efforts, including, for example, census and population surveys.

1977 standards. OMB's 1977 Statistical Policy Directive (SPD) 15 established the first federal race and ethnicity minimum standards to be used when these data are collected but did not require their collection. The directive provided four minimum standards for the racial categories (white, Black, Asian or Pacific Islander, and American Indian or Alaskan Native) and two ethnicity categories (Hispanic origin and not of Hispanic origin). More

granular categories were permitted as long as they could be aggregated into the minimum standards (OMB 1977). The inclusion of these questions in federally sponsored surveys and administrative data collection efforts is necessary for measuring racial and ethnic disparities, monitoring equal access to services, and enforcing Title VI of the Civil Rights Act (Youdelman and Hitov 2001).

1997 standards. In response to criticism that the original standards did not reflect the racial and ethnic diversity in the United States, OMB completed a comprehensive review of the standards and published updated standards informed by public comment and research. The updated SPD 15 revised the minimum federal standards to include five racial groups (white, Black or African American, Asian, American Indian or Alaska Native, Native Hawaiian or other Pacific Islander) and two ethnicity categories (Hispanic or Latino and not Hispanic or Latino) (Appendix 1A). As with the 1977 directive, these minimum standards apply only if race and ethnicity information are collected, do not require the collection of race and ethnicity data, and do not directly apply to state-level data collection and reporting, including by state Medicaid programs (OMB 1997). However, to enable its own reporting as a federal agency, CMS requires states to report race and ethnicity data to T-MSIS that at minimum meet OMB standards.[6, 7]

Considered revisions. OMB has considered revisions to the 1997 OMB standards, but no changes have yet been finalized. In 2014, OMB formed the Interagency Working Group for Research on Race and Ethnicity to improve federal race and ethnicity data. In 2016, OMB published a notice of possible revisions to the 1997 minimum standards based on the work group's recommendations. Specifically, the recommendations included asking separate questions about race and ethnicity, adding a Middle Eastern and North African (MENA) racial category, and clarifying that the proposed minimum standards do not prevent the collection of more granular race and ethnicity data (OMB 2016). However, OMB did not publish an updated rule.

In 2021, the Biden Administration established the Equitable Data Working Group to assess existing federal data collection systems and programs and to propose policy recommendations to improve race and ethnicity data availability. Its report emphasized

the importance of having federal data collection standards that reflect the diverse populations in the United States. The group recommended revising the 1997 OMB standards to include groups that are not currently represented in the minimum standards, such as MENA, and to include subgroups within the Asian and Native Hawaiian and Pacific Islander categories (Equitable Data Working Group 2022, EOP 2021).

In June 2022, the chief statistician of the United States announced that the Office of Information and Regulatory Affairs, Statistical and Science Policy Office would begin a formal review of the 1997 OMB minimum standards, with the goal of publishing revised standards by summer 2024 (Orvis 2022). On January 27, 2023, OMB proposed revisions to the 1997 OMB SPD 15 minimum standards and reiterated its plans to complete the revisions by summer 2024 (OMB 2023).[8]

HHS policies on race and ethnicity data collection

HHS developed race and ethnicity data collection standards and requirements for HHS-sponsored national population health surveys that go beyond those established by the 1997 OMB rule. Although the HHS standards apply only to population health surveys, some federal and state-level data collection efforts have implemented them.

1997 HHS data inclusion policy. HHS issued a policy statement reiterating OMB standards and outlined which HHS-sponsored data collection efforts are required to collect and report race and ethnicity information in accordance with OMB standards.[9] Before this HHS policy, HHS found inconsistencies in the collection and reporting of race and ethnicity data. The policy statement cited the lack of a requirement to include questions on race and ethnicity as one of the primary reasons for the incomparable and poor-quality data across HHS data systems (Youdelman and Hitov 2001, HHS 1997).

The applicability of the 1997 data inclusion policy to state data collection activities is unclear. While the 1997 HHS policy specifically notes the applicability of the standards to administrative records, it did not directly mention state Medicaid agencies, and CMS did not enforce the collection or reporting of these data. Despite the lack of an explicit requirement,

most states were collecting these data at the time the guidance was issued or began to in response to it (Youdelman and Hitov 2001). In 2004, about 70 percent of state Medicaid programs reported collecting race and ethnicity data. However, there was little consistency across state approaches, and few states asked questions that included all seven of the OMB minimum standards (LLanos and Palmer 2006).

2011 HHS implementation guidance on data collection standards. As required by the Patient Protection and Affordable Care Act (ACA, P.L. 111-148, as amended), HHS issued guidance on race and ethnicity data collection. Section 4302 of the ACA charged the Secretary of HHS to establish uniform data collection standards for race and ethnicity that, at a minimum, meet the 1997 OMB standards and develop data collection standards for sex, primary language, and disability status that would be consistently collected and reported across all federally conducted or supported health care data collection efforts (HHS 2011b). The ACA also required the Secretary to ensure that within two years of enactment, all federally sponsored and supported data collection should, to the extent practicable, collect data on race, ethnicity, sex, primary language, and disability status that meet the HHS standards. Additionally, Section 4302 of the ACA extended these data collection standards to state Medicaid programs and CHIP.

The 2011 HHS guidance established standards for collecting data on race, ethnicity, sex, primary language, and disability status. These updated race and ethnicity standards included more granular race and ethnicity categories that can be aggregated to meet OMB minimum standards (Appendix 1A). However, the 2011 HHS implementation guidance requires only HHS-conducted or -sponsored national population health surveys to use these minimum standards. The guidance does not specify standards that apply to other forms of federally sponsored and supported data collection, including those collected under Medicaid and CHIP state plans (HHS 2011a). HHS officials reported these guidelines were designed to apply only to survey data collection to allow for state and program flexibility given that some of these standards may not be applicable across the wide range of programs within HHS (HHS 2022c).

Although these standards do not explicitly apply to state Medicaid programs and CHIP, all states collect race and ethnicity information on their applications. Further, more than half of the states include race and ethnicity categories that align with the 2011 HHS guidance and report these data to CMS (SHADAC 2022).

State Data Collection and Reporting Processes

Medicaid race and ethnicity data collection methods and reporting processes are complex and often developed to meet state-specific needs. Multiple steps are necessary to collect, store, process, and transform the data into the final format required for submitting to T-MSIS. The varying methods states use for these processes can affect the completeness, accuracy, and overall quality of the data.
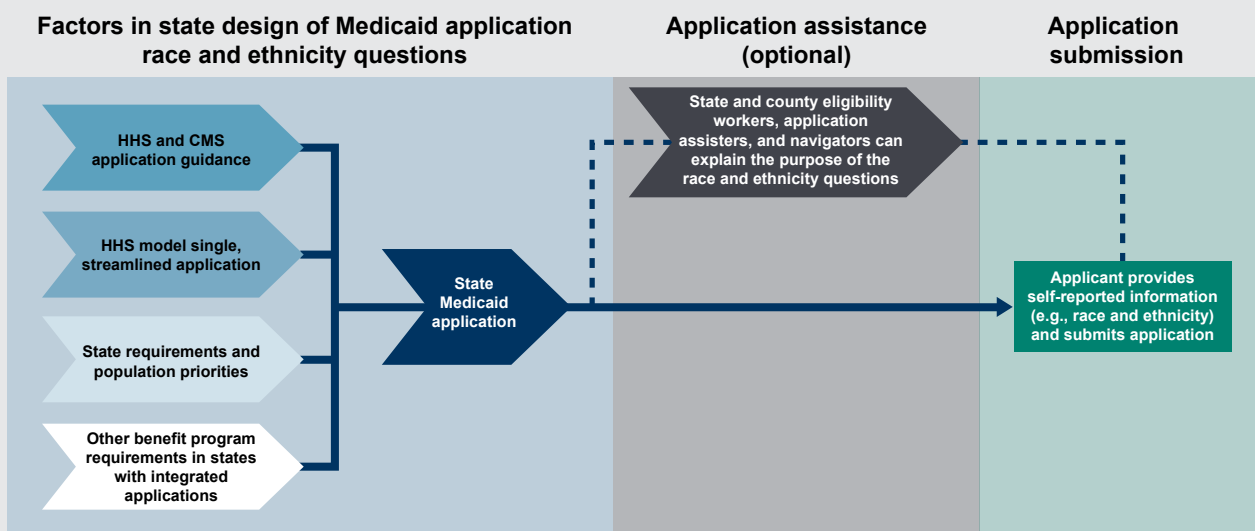
Data collection

State Medicaid programs develop their own applications. States are permitted to include only optional race and ethnicity questions on

the application, as they are not a requirement of Medicaid eligibility. Race and ethnicity are typically self-reported by applicants, which is considered the preferred method for collecting data to best reflect the individual's identity (OMB 1997). Individuals can complete the application online, in person, over the phone, and, if needed, with the assistance of state- and county-level Medicaid application assisters, caseworkers, and other organizations with trained application assisters and navigators (Figure 1-1).

Application development. States have the flexibility to determine which race and ethnicity categories to include on their applications as long as the collected information allows the state to meet CMS-established reporting requirements (CMS 2022b).

In 2013, CMS provided states with a model single, streamlined application to be used to determine enrollment for Medicaid, CHIP, and qualified health plans on exchanges.[10] The model application includes optional race and ethnicity questions that align with the 2011 HHS data collection standards, which aggregate to OMB standards, and allow individuals to select multiple races and ethnicities in their responses. They do not include an option for individuals to indicate that they prefer not to provide their race and ethnicity

FIGURE 1-1. State Application Development and Race and Ethnicity Data Collection Processes

Factors in state design of Medicaid application race and ethnicity questions

- HHS and CMS application guidance
- HHS model single, streamlined application
- State requirements and population priorities
- Other benefit program requirements in states with integrated applications

State Medicaid application

Application assistance (optional)

State and county eligibility workers, application assisters, and navigators can explain the purpose of the race and ethnicity questions

Application submission

Applicant provides self-reported information (e.g., race and ethnicity) and submits application

Notes: HHS is U.S. Department of Health and Human Services. CMS is Centers for Medicare & Medicaid Services.

Source: MACPAC analysis of race and ethnicity data collection process.

information, so those who choose not to respond leave these questions blank (CMS 2013a).

CMS also provided states with guidance on how to modify the model application or develop a state alternative application for CMS approval.[11] States are permitted to submit an alternative application to allow for state-specific needs and policies, as long as the application still complies with the general principles of the model application. For example, states can only require questions that are necessary for determining eligibility, and other included questions, such as those on race and ethnicity, are permitted only as optional questions. However, the guidance did not include specific information related to the inclusion or modification of the model application race and ethnicity questions (CMS 2013b).

Many states have modified or developed their own CMS-approved applications. A review of all state paper and online applications found states collect race and ethnicity information in 64 different ways, including variations in the questions and categories provided on online and paper applications. The majority of states include categories that are consistent with OMB standards or 2011 HHS standards, but many states include additional categories that expand on the 2011 HHS standards. Additionally, some states allow applicants to select multiple races and ethnicities, while other states allow only one selection, and a few have a combined race and ethnicity question. Further, some state race and ethnicity questions vary between paper and online applications. For example, some states, due to space limitations, include fewer categories to choose from on paper applications than on online applications (SHADAC 2022).[12]

Some states modified the race and ethnicity questions based on state requirements or population priorities. For example, one state's data collection standards were determined by state statute, which required 33 race and ethnicity options and additional options for individuals to choose unknown race or ethnicity or to decline to answer. The categories were developed based on research-supported practices and were informed by a community stakeholder process. Another state is developing a new application that will include race and ethnicity questions with categories that align with OMB standards and an additional question with a more extensive list of ethnicities that was determined based on the state's population diversity. The data

from this additional question will be used for state-level reporting and analyses to measure health disparities for populations of interest for the state. These changes were informed by an advisory group and a request for information on the data standards.

States also have the option to integrate their Medicaid eligibility systems with other benefit programs, so some state applications are developed to meet the requirements for multiple programs. For example, 29 state Medicaid programs have multi-benefit applications that are also used to determine eligibility for the Supplemental Nutrition Assistance Program (SNAP) (Brooks et al. 2022). In our interviews, state officials noted their multi-benefit applications must meet both federal Medicaid and SNAP requirements. Federal SNAP data collection requirements are more specific compared with Medicaid. SNAP applications are required to include race and ethnicity questions with categories that meet OMB minimum standards, although states are permitted to include additional race categories.[13] Applicants must also be given the option to select multiple races, and SNAP provides states with suggestions for how to collect multiple selection responses.[14]

Role of application assisters. A variety of application assisters help individuals enroll in Medicaid and many other benefit programs. Examples of assisters include federal- and state-funded workers, such as navigators, state and county eligibility workers, community health center outreach workers, and other organizations that provide application assistance services. Almost one in five of those who applied for or renewed coverage in 2020 reported receiving assistance when applying for coverage (Pollitz et al. 2020). Additionally, application assistance is in high demand, especially by certain populations, such as mixed-coverage families, populations in highly transient or largely immigrant communities, and individuals with lower computer literacy (MACPAC 2018).

Trainings for application assisters, navigators, and state and county eligibility workers are developed at the federal, state, and organization level. CMS provides Federally Facilitated Marketplace assister training, which navigators are required to complete before helping individuals enrolling through the federal exchange. Federally funded navigators assist all individuals who apply through the health insurance exchange, including individuals who are ultimately determined eligible for Medicaid, CHIP, or other

insurance affordability programs. The training includes multiple modules about serving vulnerable and underserved populations. However, it does not include any information related to asking the optional race and ethnicity questions (CMS 2022c, Sheedy 2014).

States often develop their own trainings, which may include specific information on asking about race and ethnicity. For example, one state, where more than 75 percent of applicants apply in person with a state eligibility worker, provides eligibility workers with training on how to ask race and ethnicity questions and reported that most applicants are willing to provide this information. However, few states we interviewed could confirm how often the trainings are offered and whether they discuss how to ask and explain the purpose of the race and ethnicity questions.

Application assister organizations also reported that state Medicaid programs provided them with Medicaid eligibility and enrollment training, although training specific to race and ethnicity questions was not consistently available. Application assisters often receive training related to race and ethnicity from external organizations or develop their own tools to help assisters explain how race and ethnicity data are used. For example, one application assister organization that serves primarily MENA populations shared that they developed their own training on how to ask race and ethnicity questions to better prepare their staff to assist applicants.

Data reporting

State Medicaid programs store and transfer the collected application information between multiple data systems that are used for CMS reporting processes and for internal state analyses (Figure 1-2). First, the eligibility data are stored in the state eligibility and enrollment (E&E) system, which is the state system used to store Medicaid application data and determine

FIGURE 1-2. State Data Reporting Process to the Transformed Medicaid Statistical Information System (T-MSIS)
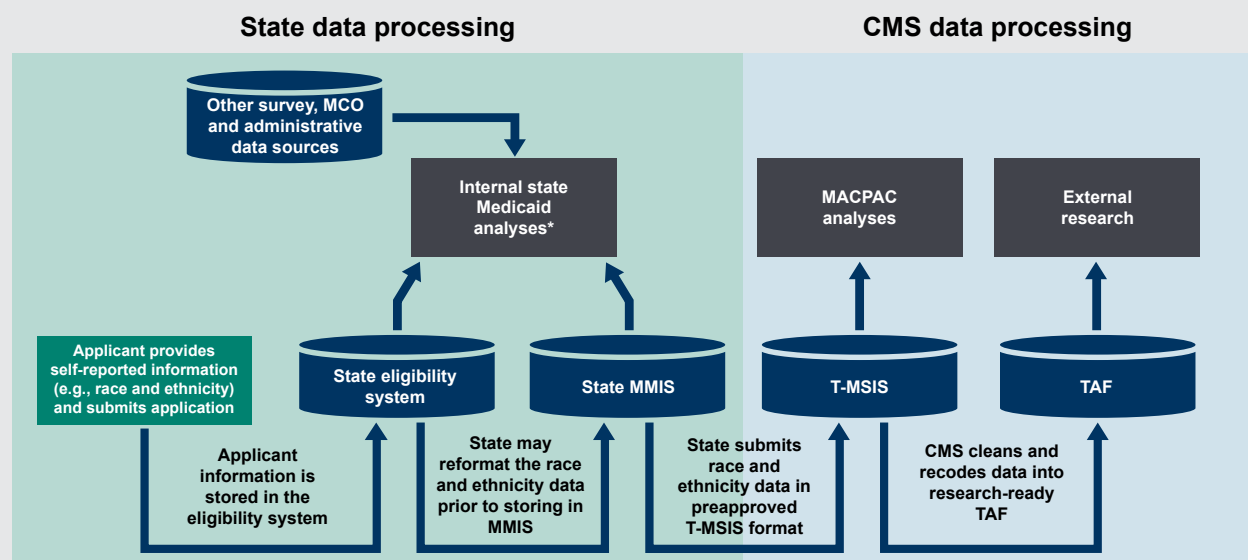
Notes: CMS is Centers for Medicare & Medicaid Services. MCO is managed care organization. MMIS is Medicaid Management Information System. TAF is T-MSIS Analytic Files.

* In addition to states using eligibility and MMIS data for internal race and ethnicity analyses, some states supplement these data with other state data sources (e.g., other survey data, managed care organization data, and other administrative data sources). However, these data sources are never used to update the state eligibility system or MMIS or change the data submitted to T-MSIS.

Source: MACPAC analysis of race and ethnicity data collection process.

Medicaid eligibility.[15] The data from the state E&E system are then transferred to the state MMIS. The MMIS stores and maintains Medicaid enrollee data and is used to manage the state Medicaid program (GAO 2020).[16] Some states collect information in a format that is not supported by the state MMIS, so the data require reformatting before the transfer from the eligibility system to the MMIS.

The data stored in the state MMIS are used to create the T-MSIS data file. The file is formatted to meet the CMS reporting requirements, including aligning the MMIS race and ethnicity categories with OMB and 2011 HHS reporting standards. States must submit all collected race and ethnicity data, so in cases in which individuals selected multiple races or ethnicities on the application, states can submit multiple values for the individual to T-MSIS (CMS 2022b).

After T-MSIS data are submitted, they are processed by CMS and released as the research-ready T-MSIS Analytic Files (TAF). The TAF data are designed to be a research-ready version of the T-MSIS data that include data on Medicaid and CHIP enrollment, demographics, service utilization, and payments. Race and ethnicity data are included in three variables in the TAF: (1) ethnicity only, aligned with the 2011 HHS categories; (2) combined race and ethnicity, aligned with OMB minimum standards; and (3) combined race and ethnicity, aligned with 2011 HHS standards (ResDAC 2022).[17]

Medicaid Race and Ethnicity Data Quality

Some state Medicaid programs have difficulty collecting and reporting complete and accurate race and ethnicity data to T-MSIS, and the quality of the data varies by state (SHADAC 2022, CMS 2021b). CMS uses several tools to assess state-level data quality and usability and provides technical assistance to improve state-submitted T-MSIS data.

Technical assistance

CMS provides state Medicaid programs with technical instructions, technical assistance, and tools to report, assess, and identify approaches to improve the

quality of the data submitted to T-MSIS. The technical instructions describe how to format and report race and ethnicity data to T-MSIS and provide a codebook for mapping race and ethnicity codes, instructions for how to code and report multiple race and ethnicity values, and examples of how to calculate some of the data quality measures used for the quality assessment (CMS 2022b). The technical assistance includes monthly meetings with states to discuss data quality improvement priorities and quarterly webinars on using the data quality assessment tools. CMS assesses the quality of the race and ethnicity data using several measures, such as data missingness. These assessments provide CMS and states with information about what is needed to improve the data submitted to T-MSIS and identify state technical assistance needs.[18]

In February 2022, CMS transitioned data quality tracking to the new Outcomes Based Assessment (OBA) to identify data concerns and assess how to address them.[19] In response to the CMS health equity focus to expand the reporting of standardized data, CMS added race and ethnicity as an OBA focus area, providing states with a more targeted assessment of their data quality and specific data measures for tracking data improvement (CMS 2022b, CMS 2022d).

The technical assistance provided to states focuses on assessing state data quality concerns and targeting critical and high-priority issues. Once CMS and the states determine which areas need improvement, the state and the state's information technology vendor develop plans to improve the data quality.[20] Some of these changes are straightforward, but some data quality issues may require large system enhancements that can take years to address.

The focus of CMS-provided technical assistance and use of data quality tools differs among states. The majority of states interviewed received technical assistance from or reported regular communications with CMS or its data contractor, Mathematica, regarding T-MSIS data quality. A couple of states with low-quality race and ethnicity data shared that efforts to improve these data were at the state level, and they had not received specific technical assistance from CMS directing them to improve these data. Additionally, some states shared issues with mapping state collected data to the T-MSIS format, but in conversations with CMS and other experts, some of these issues are due to the

design of state-level systems, and overall, these issues are becoming less common.

Data quality assessment tool

After the initial state-level data assessment, CMS uses the Data Quality (DQ) Atlas tool to assess state race and ethnicity data quality and its usability for analytical work. In the most recent assessment of TAF race and ethnicity data, CMS determined that 31 states have usable data for analyses, and 19 states and the District of Columbia have unusable data (Figure 1-3).

The CMS DQ Atlas assessment uses two criteria to measure race and ethnicity data quality. The first is data completeness, which is defined as the percentage of records with non-missing values. In the 2020 data quality assessment, 18 states were missing more than 20 percent of race and ethnicity data.[21] The percentage of missing data varies by state, with some states reporting this information from nearly all applicants and others reporting these data from fewer than half of applicants (CMS 2021a).

The second criteria is data accuracy, which uses the American Community Survey (ACS) as a benchmark for the TAF race and ethnicity data. Accuracy is assessed by the number of combined race and ethnicity categories for which the TAF and the ACS Medicaid population estimates differ by less than 10 percent.[22] In the 2020 quality assessment, 28 states reported at least one race or ethnicity category for which the TAF percentage differed from the ACS Medicaid population benchmark by more than 10 percent (CMS 2021a).[23]

FIGURE 1-3. Centers for Medicare & Medicaid Services Data Quality Assessment of Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files Race and Ethnicity Data, FY 2020

Low concern (15)   Medium concern (16)   High concern (16)   Unusable (4)

Note: FY is fiscal year.

Source: CMS 2021a.

TABLE 1-1. Race and Ethnicity Code Data Quality Assessment Criteria

Percentage of records with missing values	Number of race and ethnicity categories for which TAF differs from ACS by more than 10 percent	Data quality assessment
x ≤ 10 percent	0	Low concern
x ≤ 10 percent	1 or 2	Medium concern
x ≤ 10 percent	3 or more	High concern
10 percent < x ≤ 20 percent	0 or 1	Medium concern
10 percent < x ≤ 20 percent	2 or more	High concern
20 percent < x ≤ 50 percent	Any value	High concern
x > 50 percent	Any value	Unusable

Notes: TAF is Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files. ACS is American Community Survey.

Source: CMS 2021a.

CMS combines these two criteria to assign states a data quality assessment of low, medium, or high concern or unusable. States with low- and medium-concern data are considered states with usable data for analyses. These states typically have either complete and accurate data or have only minimal concerns with one of these two criteria. States with high-concern or unusable data are not considered usable for analyses. These states have high rates of missing data, misalignment between the TAF and ACS benchmark, or issues with both criteria (Table 1-1).

The overall quality of TAF race and ethnicity data has been consistent over the past four years, with only one or two states improving or declining in quality year to year (Figure 1-4). Since 2017, 39 states have been assigned the same data quality assessment in all four years; 10 states' data quality improved, with three improving from the high concern or unusable categories to medium or low concern; and three states' data quality worsened and no longer report usable data for analyses.

Challenges with Improving Data Quality

High-quality T-MSIS race and ethnicity data need to be comparable to allow for national and state-level analyses, and the meaningfulness of the comparisons rely on the data being complete and accurate. There are many challenges with collecting and reporting these data that may limit the ability to measure health disparities. Although it may not be feasible to collect race and ethnicity data from all applicants, research has shown that data are often not missing at random. Therefore, when a large proportion of data are missing, the data do not represent the whole population and can mask health disparities of underrepresented populations (James et al. 2021a, Labgold et al. 2021, Sholle et al. 2019).

Although all state Medicaid programs collect race and ethnicity information, many states have challenges with gathering these data from applicants due to applicant willingness to respond or understanding of the questions. Applicants may skip these questions because they are concerned about how the information may be used, including fear of being denied coverage. For example, one assister organization shared that some applicants who had previously been denied coverage were worried that providing additional, optional information could lead to another denial. Applicants may also not understand how to respond to the questions, especially when categories do not align with how they self-identify. For example, one organization that serves primarily MENA populations shared that many individuals will check "other" and write in their country of origin rather than select one of the provided categories.

FIGURE 1-4. Centers for Medicare & Medicaid Services Data Quality Assessment of State Medicaid Race and Ethnicity Data, FYs 2017–2020
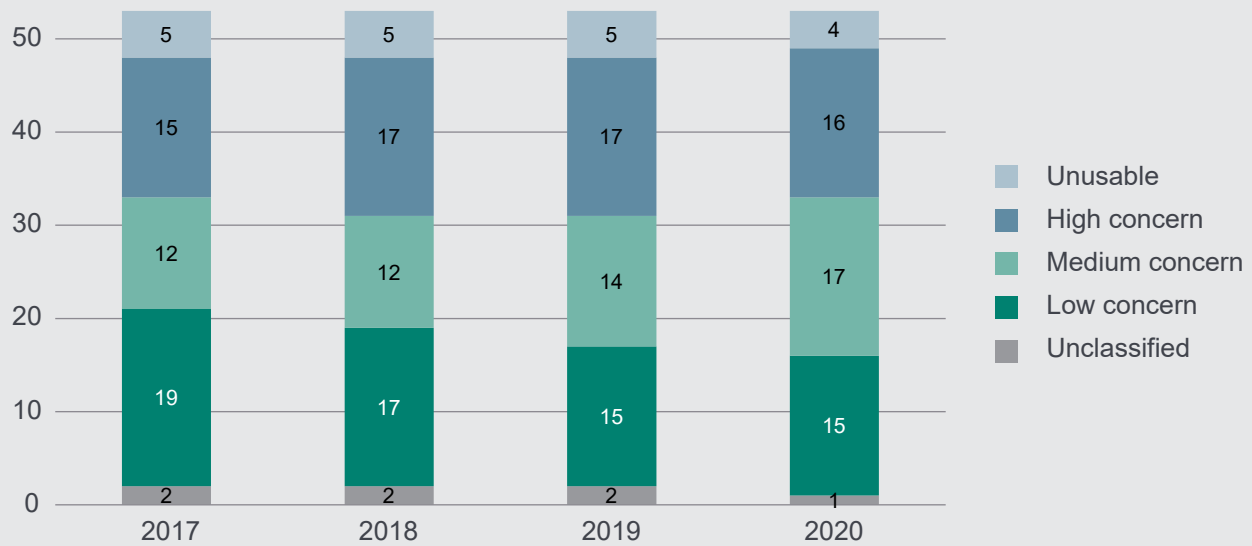
Notes: FY is fiscal year. Results are from the Centers for Medicare & Medicaid Services Data Quality (DQ) Atlas, assessing the quality and usability of 2017–2020 Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF) race and ethnicity data for 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands. The counts represent the number of states, territories, and the District of Columbia with race and ethnicity data that are considered usable (low or medium concern), unusable (high concern and unusable) for statistical analyses, or unclassified by the DQ assessment because the territory was missing American Community Survey benchmark data (CMS 2021a).

Source: TAF 2017–2020 (CMS 2022d).

Many states have difficulty reporting data because of misalignment among how state eligibility systems, MMIS, and T-MSIS store and format race and ethnicity data. While many states have eligibility systems and MMIS that collect and store race and ethnicity in categories that facilitate simple one-to-one mapping with the T-MSIS formatted categories, some states do not. Before submitting the data to T-MSIS, these states must reformat and aggregate the data, which can sometimes affect the quality of the submitted data (Saunders and Chidambaram 2022, SHADAC 2022). For example, three states collect MENA categories; however, when these states aggregate the data to align with T-MSIS categories, that granularity is not reported (SHADAC 2022). Additionally, some states' eligibility systems and MMIS are misaligned, which can lead to diminished data quality during the transfer process. For example, two states that collect multiple race and ethnicity selections shared that the state MMIS was not designed to store multiple selections.

Therefore, in these states, the individual's more detailed information is not included in the data that are submitted to T-MSIS.

Approaches to addressing challenges

During our research, several potential approaches to improving the collection and reporting of complete and accurate Medicaid race and ethnicity data emerged. One approach focused on providing states with an updated model application using evidence-based approaches to race and ethnicity questions that have been shown to improve applicant response rates and data accuracy. For example, the U.S. Census Bureau found that response rates increased when using a combined race and ethnicity question and with the wording "Select all boxes that apply" rather than "Select one or more boxes" for multiple selections.[24] Including the MENA category improved data accuracy because these individuals reported that without this option,

they were unsure of how to self-identify (Matthews et al. 2017). Further, a recent state-based study found that requiring applicants to respond to the race and ethnicity question, which included an opt-out response of "Don't know" or "Choose not to answer," led to a substantial increase in response rates for both the race and ethnicity questions (NYSOH 2021, Planalp 2021). Additionally, some states have begun to include language on the application to describe how these data will be used or clarify that providing the information will not affect their eligibility (SHADAC 2022).

Another approach involved providing all types of assisters (e.g., state and county eligibility workers, application assisters, navigators, and anyone else who may assist individuals with the application process) with model training materials that include information to share with applicants that could improve their trust in providing their race and ethnicity. For example, some application assister organizations have developed trainings for explaining the purpose of these questions and uses of the data to help assisters answer applicant questions. Providing all types of assisters with training materials about these questions and providing them with template language to use with applicants has improved their comfort and trust in sharing sensitive information (James et al. 2021a, Baker et al. 2005).

There are also promising federal and state efforts to improve data reporting. CMS provides targeted technical assistance to all states to help them identify and address data reporting issues, as described previously. Some states are also working to resolve system issues. For example, two states are in the process of redesigning their eligibility system and MMIS to store race and ethnicity data in a format that supports both state needs and federal reporting requirements. CMS should continue to prioritize improving race and ethnicity data reporting and provide states technical assistance until all states are able to submit usable data for analyses.

MACPAC's recommendations to improve Medicaid application questions and application assister training aim to address the primary challenges with collecting race and ethnicity data. In conjunction with ongoing work at the federal and state levels to address other challenges, these recommendations may also lead to improvements in the completeness and accuracy of race and ethnicity data collected from Medicaid applicants.

Commission Recommendations

Recommendation 1.1

The Secretary of the U.S. Department of Health and Human Services (HHS) should update the model single, streamlined application to include updated questions to gather race and ethnicity data. These questions should be developed using evidence-based approaches for collecting complete and accurate data. The updated application should include information about the purpose of the questions so that the applicant understands how this information may be used. HHS should also direct the Centers for Medicare & Medicaid Services to update guidance on how to implement these changes on a Secretary-approved application.

Rationale

Updating the model application race and ethnicity questions and the guidance for implementing these changes on state-designed applications would help to address some of the challenges with collecting complete and accurate race and ethnicity information. The model application has not been updated since it was first released in 2013, and there are more recent evidence-based approaches that can improve response rates. Further, updated guidance is needed to explain how these changes can be implemented on state-designed applications given that the majority of states have made modifications to the model application or developed an alternative application. This approach maintains state flexibility to customize their applications based on their own programmatic needs and priorities, while also enabling them to collect data in a format that can be aggregated to support federal reporting standards and cross-state analyses.

As with the 2013 model single, streamlined application, the development process for updating the application and race and ethnicity questions should include public comment, stakeholder consultation (including states, beneficiaries, and assister organizations), and consumer testing before implementation (CMS 2013a). Furthermore, the application questions should implement user-tested and research-based approaches that have been shown to help improve the collection of complete and accurate data. For example,

these approaches could include using a combined race and ethnicity question, requiring a response to the questions on online applications with a selection to opt out of a response, and adding options to select "Don't know" or "Choose not to answer" on both online and paper applications. In addition, the application should include language explaining the purpose of the race and ethnicity questions. This additional information should be included on all translated versions of the applications (Planalp 2021, Matthews et al. 2017). Ensuring applicants understand the reasons for collecting race and ethnicity data, how these data may be used by federal and state governments, and that their response does not affect their eligibility has been shown to make them feel more comfortable providing sensitive information.

HHS should consider the implications of any changes to the model application for purposes of Medicaid data collection on other programs serving Medicaid beneficiaries and should coordinate any updates with other Administration-wide efforts. For example, changes to the race and ethnicity questions could affect states with multi-benefit applications as well as those that use the federal exchange, which also relies on the HHS model application. Additionally, HHS should coordinate any updates with the revisions to the OMB minimum standards, which are anticipated by summer 2024 (Orvis 2022).

The Commission also underscores the importance of coordinating efforts to update the model application with the possible collection of additional demographic information. Questions about other demographic characteristics, such as sexual orientation, gender identity, and disability status, are often excluded or not asked using comparable methods. Collecting data on these populations is needed to understand their experiences accessing and using Medicaid services, but additional work is required to determine the most appropriate methods to collect these data.

Implications

Federal spending. The Congressional Budget Office assumes that this policy would not affect federal spending. Updating the model, single streamlined application could lead to increases in administrative costs in the short term as the new application is developed and implemented, including in matching costs to the states for any associated systems

changes. Furthermore, coordinating any updates to the applications with anticipated revisions to race and ethnicity standards and other demographic data may minimize costs.

States. In the process of updating the model application, states may participate in developing the application or in the review process, which may lead to short-term costs to states. Additionally, there may be operational costs with implementing changes to data collection on the application and the reporting of these data to CMS. For example, it is anticipated that system upgrades may be necessary, which may lead to additional state costs. However, these costs would likely be eligible for a higher federal matching rate.

Enrollees. To the degree that improved data collection increases the ability for CMS and state Medicaid programs to assess and address disparities, there might be improved enrollee experience.

Plans and providers. State updates to race and ethnicity data collection could lead to increased costs to plans and providers. For example, to align with updated state Medicaid data collection standards, plans may need to make system changes to adopt these standards or to meet new state contracting requirements. Plans and provider ability to meet health equity accreditation and outreach to beneficiaries may also benefit with improved data completeness and accuracy.

Recommendation 1.2

The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services to develop model training materials to be shared with state and county eligibility workers, application assisters, and navigators to ensure applicants receive consistent information about the purpose of the race and ethnicity questions. The training materials should be developed with the input of states, beneficiaries, advocates, and application assisters and navigators, user tested prior to implementation, and adaptable to state and assister needs.

Rationale

Providing state and county eligibility workers, navigators, and application assisters funded by the state and other community-based assisters with training materials on how to ask applicants for race

and ethnicity information is an important component in improving applicant trust when providing sensitive information. Individuals often seek assistance during the application process, affording assisters with the opportunity to explain the purpose and value of responding to the race and ethnicity questions (CMS 2022c, MACPAC 2018). Research has shown that providing application assisters and navigators with a script to educate individuals about why the application asks these questions and how the information will be used can improve the applicant's comfort with responding (James et al. 2021, NYSOH 2021, Planalp 2021, Baker et al. 2005).

State eligibility workers and assisters receive training to assist applicants, but they do not consistently receive specific training on asking the race and ethnicity questions. CMS provides the Federally Facilitated Marketplace assister training, but it does not include information on asking optional race and ethnicity questions (CMS 2022c). Some states also develop trainings, but they are inconsistently provided to assisters.

CMS should develop training materials that specifically address how to ask the race and ethnicity questions and continue to update these materials to reflect the most recent evidence on how to increase applicant understanding and willingness to respond. These materials should inform the Federally Facilitated Marketplace assister training materials as well as materials provided to state Medicaid programs, assister organizations, community organizations, providers, plans, and any other organizations that may assist with the application process. The training materials should be developed with input from stakeholders, including states, beneficiaries, and assisters, and draw on research. The training materials should be designed to both educate assisters and provide them with sample language to use when speaking to applicants. CMS should also provide states with technical assistance to modify the training to reflect state-specific populations and application details, and the training should be customizable for assister organizations that are serving specific populations.

Implications

Federal spending. The Congressional Budget Office assumes that this policy would not affect federal spending. Developing new training materials could lead to increases in federal costs in the short term as the new materials are developed and implemented. Anticipated revisions to race and ethnicity standards and other demographic data may lead to additional costs if updates to the training materials are needed to reflect future changes on the model application.

States. States are working to improve the completeness and accuracy of their race and ethnicity data. States not currently providing training materials, but that adapt the CMS-provided training materials for state-specific needs, may have an increase in short-term costs. For states that have developed and invested in training materials, the additional effort to update the materials could be minimal. Additionally, there may be costs for states if they provide trainings to assister organizations and other types of organizations that may interact with applicants.

Enrollees. To the degree that revised training materials lead to improved application assistance provided to enrollees and increased enrollee understanding of the purpose of these data, enrollees may experience an improved application process.

Plans and providers. Plans and providers that serve in an assister or navigator role may need to adapt their training materials to implement these updates, which may lead to some short-term costs. These new trainings may also improve their ability to assist individuals applying for Medicaid.

Endnotes

[1] Other potential federal- and state-level data sources include the Health Resources and Services Administration and state-level managed care data. Other data sources, such as Centers for Medicare & Medicaid Services claims forms (e.g., CMS-1450 and CMS-1500), could be useful for collecting race and ethnicity information. However, T-MSIS is the only data source that includes information about all Medicaid beneficiaries, making it the primary data source for Medicaid-specific analyses.

[2] Using methods developed by CMS, MACPAC analyzed the raw T-MSIS race and ethnicity data to assess their completeness and accuracy (MACPAC 2022b, CMS 2021a).

[3] Interviewees included state officials from Hawaii, Kentucky, Maryland, Massachusetts, Nevada, North Carolina, and Oregon; research and policy experts from the National Health Law Program, State Health Access Data Assistance Center at the University of Minnesota, and Mathematica; application assisters from ACCESS Community Health and Research Center, Georgians for a Healthy Future, Public Health Solutions, and WithinReach; and managed care organizations and health plan associations, including Priority Partners and the Blue Cross Blue Shield Association.

[4] Recent research indicates that the demographic and health characteristics of individuals not reporting race and ethnicity information differ from those who do, suggesting race and ethnicity data are missing not at random. Therefore, standard analytical methods that assume the race and ethnicity information are representative of the full population will most likely produce results that are biased and underestimate racial and ethnic disparities.

[5] The report found that the imputation algorithm performed best with regard to enrollees who identified as Asian American, Native Hawaiian, and Pacific Islander; Black; Hispanic; or white and was not as reliable for enrollees who identified as American Indian and Alaska Native or multiracial.

[6] In addition to the OMB minimum standards, states do have the option to report more granular categories to CMS. T-MSIS includes the option for states to report race and ethnicity information that align both with the OMB categories and the more granular 2011 HHS categories (HHS 2011a, OMB 1997).

[7] Although this work does not specifically focus on the collection and reporting of race and ethnicity data for CHIP, the T-MSIS data reporting requirements are the same for Medicaid and separate CHIP.

[8] The purpose of the revisions is to ensure the race and ethnicity questions and categories reflect the populations in the United States. The proposed revisions include collecting race and ethnicity in a singular question, adding Middle Eastern and North African as a new minimum category, requiring the collection of more granular categories, and updating the terminology and definitions in SPD 15 (OMB 2023).

[9] The 1997 HHS inclusion policy applies to the following HHS-sponsored data collection and reporting activities: statistical data collection; administrative records; research, evaluation, and other study projects; applications, grants, and contract proposals submitted to HHS and its agencies or major operating components that collect data from the public; and reporting systems for civil rights compliance (HHS 1997).

[10] The ACA included provisions to streamline eligibility, enrollment, and renewal processes, including requiring a single application for Medicaid, CHIP, and subsidized exchange coverage. In 2013, CMS released federal guidance for developing applications, including a model single, streamlined application (CMS 2013a, 2013b).

[11] The review and approval of the application occurs through the State Plan Amendment process.

[12] The majority of states include race and ethnicity categories that align with OMB or HHS standards, but the number of categories included on Medicaid applications vary by state and sometimes between paper and online applications within a state. For example, 7 state paper application and 7 state online application race categories align with OMB standards, and 12 state online application and 13 state paper application ethnicity categories align with OMB standards. Some states include additional categories that align with HHS guidance. For example, 27 state online application and 6 state paper application race categories align with HHS guidance, and 6 state online application and 28 state paper application ethnicity categories also align with HHS guidance (SHADAC 2022).

[13] The Food and Nutrition Service (FNS) established application requirements for all FNS programs. For example, all state FNS agencies are required to obtain race and ethnicity information for all applicants according to prescribed specifications. Race and ethnicity must be collected using a two-question format and the minimum categories must align with OMB standards. States are permitted to include additional categories for race only. Ethnicity must be collected before race, and applicants have the option to choose multiple race categories (FNS 2005).

[14] One state with an integrated application developed an alternative approach to multiple selection. The state application includes predetermined multiracial category combinations, and individuals who do not identify with the options provided can select an "other" multiracial category.

[15] The E&E system is used for many state functions, including storing state Medicaid application information; determining eligibility for enrollment, renewals, and change in circumstances; and supporting enrollment into the appropriate program. Some states have integrated the E&E system with other public programs, and in these states the E&E system will store and determine eligibility for these additional programs (GAO 2020).

[16] State Medicaid programs are required to have an MMIS to be eligible for federal funding. The MMIS supports the management of the state Medicaid program and is the source for state-submitted eligibility and claims data (CMS 2021c).

[17] The TAF research-ready file is created using T-MSIS data. The TAF includes two combined race and ethnicity variables, one aligning with OMB categories and one aligning with 2011 HHS guidance variables. The OMB category variable includes seven race and ethnicity categories and a multiracial category, created from the multiple race and ethnicity values available in T-MSIS. This race and ethnicity variable is used in the Data Quality (DQ) Atlas to assess the quality of the race and ethnicity (CMS 2021a).

[18] States submit monthly reports to T-MSIS. CMS evaluates these state-submitted race and ethnicity data using four primary criteria: (1) the percentage of MSIS IDs with unspecified, unknown, missing, or invalid race and ethnicity codes; (2) the rate of missing segment effective dates on the segment that includes the race and ethnicity data; (3) the percentage of MSIS IDs with the American Indian and Alaska Native indicator turned on that do not have American Indian and Alaska Native reported as the race value; and (4) the index of dissimilarity for either the race or the ethnicity data element that indicates changes in the response distribution month over month (Mathematica 2023).

[19] Before the development of the Outcomes Based Assessment, CMS used the T-MSIS Priority Items (TPIs) Data Quality Tool. CMS identified 32 TPIs to help states identify, track, and set priorities for their data quality issues and focus areas. The TPIs were based on state reporting requirements, and if states were unable to comply with the requirements for a TPI, it was flagged as a data quality issue for the state (CMS 2021d).

[20] In addition to CMS data quality assessments, some states also conduct internal validation and analyses to improve data quality. For example, one state regularly monitors changes in data quality within its eligibility system and works with state agency partners and MMIS vendors to improve its

data. Some states conduct internal processes that mimic the CMS DQ Atlas and Outcomes Based Assessment criteria, and others validate their administrative data against other state eligibility reports to review the distribution of race and ethnicity data.

[21] The DQ Atlas assesses missing data based on the combined TAF race and ethnicity variable. If neither the race nor ethnicity codes are provided in the source T-MSIS data, the race and ethnicity flag in TAF will be set to null, indicating the data are missing. Additionally, if the ethnicity code is equal to zero (a valid value indicating non-Hispanic ethnicity) and the race code is missing in the source T-MSIS data, the race and ethnicity flag in TAF will be set to null. However, if the ethnicity code is missing and the race code is non-missing in T-MSIS, then the race and ethnicity code in TAF is set equal to the reported race code in T-MSIS (CMS 2021a).

[22] The Medicaid population within the ACS includes all individuals who reported having "Medicaid, Medical Assistance, or any kind of government-assistance plan for those with low incomes or a disability."

[23] The TAF distribution includes missing race and ethnicity information in the denominator. Although there are some benefits to excluding non-missing data from the denominator, including missing information in the denominator can help DQ Atlas users and researchers evaluate whether a state has a high rate of missing data for only one or two of the race and ethnicity categories. This can be important for evaluating whether the data are accurately representing the state population (Mathematica 2022).

[24] In 2015, the Census Bureau examined multiple dimensions of these questions, including the question format, the response categories, and instructions, and tested multiple approaches to asking these questions to improve the quality and usability of the collected data for the 2020 Census (Matthews et al. 2017).

References

Akard, J. 2022. Improving health equity in Medicaid: State policy innovation and research. *Academy Health Blog Post*, March 2. https://academyhealth.org/blog/2022-03/improving-health-equity-medicaid-state-policy-innovation-and-research.

Baker, D.W., K.A. Cameron, J. Feinglass, et al. 2005. Patients' attitudes toward health care providers collecting information about their race and ethnicity. *Journal General*

Internal Medicine 20, no.10: 895–900. https://pubmed.ncbi. nlm.nih.gov/16191134/.

Brooks, T., A. Gardner, A. Osorio, et al. 2022. Integration of Medicaid and non-health program eligibility systems. Washington, DC: KFF. https://www.kff.org/health-reform/ state-indicator/integration-of-medicaid-and-non-health-program-eligibility-systems/.

Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. 2022a. *CMS framework for health equity 2022–2032*. Baltimore, MD: CMS. https://www.cms.gov/files/document/cms-framework-health-equity.pdf.

Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. 2022b. *CMS technical instructions: Reporting race and ethnicity in the T-MSIS eligible file*. https://www.medicaid.gov/medicaid/data-and-systems/macbis/tmsis/tmsis-blog/109701.

Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. 2022c. Training for navigators, agents, brokers, and other assisters. Baltimore, MD: CMS. https://marketplace.cms.gov/technical-assistance-resources/training-materials/training.

Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. 2022d. *DQ Atlas: DQ assessment of race and ethnicity*. Baltimore, MD: CMS. https://www.medicaid.gov/dq-atlas/landing/topics/ single/map?topic=g3m16&tafVersionId=25.

Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. 2021a. *DQ Atlas background and methods resource: Race and ethnicity*. Baltimore, MD: CMS. https://www.medicaid.gov/dq-atlas/ downloads/background_and_methods/TAF_DQ_Race_ Ethnicity.pdf.

Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. 2021b. *A new method to improve measurement of race-and-ethnicity in CMS data and applications to inequities in quality of care*. Baltimore, MD: CMS. https://www.cms.gov/files/document/ new-method-improve-measurement-race-and-ethnicity-cms-data-and-applications-inequalities-quality.pptx.

Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. 2021c. Medicaid data sources—general information. Baltimore, MD: CMS. https://www.cms.gov/Research-Statistics-Data-and-Systems/ Computer-Data-and-Systems/MedicaidDataSourcesGenInfo.

Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. 2021d. CMS technical instruction: Overview of data quality T-MSIS priority items. https://www.medicaid.gov/medicaid/data-and-systems/ macbis/tmsis/tmsis-blog/entry/54044.

Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. 2013a. CMCS informational bulletin regarding "Model eligibility application and guidance on state alternative applications." April 30. https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/CIB-04-30-2013_78.pdf.

Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. 2013b. CMCS informational bulletin regarding "Guidance on state alternative applications for health coverage." June 18. https:// www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/state-alt-app-guidance-6-18-2013.pdf.

Chau, V., and P. Chan. 2021. One size does not fit all: Appreciating the diversity of Asian Americans, Native Hawaiians, and Pacific Islanders (AANHPIs) and the implications for mental health. *SAMHSA Blog*, May 25. https://www.samhsa.gov/blog/one-size-does-not-fit-all-appreciating-diversity-asian-americans-native-hawaiians-pacific.

Dembosky, J.W., A.M. Haviland, A. Haas, et al. 2019. Indirect estimation of race/ethnicity for survey respondents who do not report race/ethnicity. *Medical Care* 57, no.5: e28–e33. https://www.ingentaconnect.com/content/wk/ mcar/2019/00000057/00000005/art00001.

Equitable Data Working Group. 2022. *A vision for equitable data: Recommendations from the equitable data working group*. Washington, DC: Equitable Data Working Group. https://www.whitehouse.gov/wp-content/uploads/2022/04/ eo13985-vision-for-equitable-data.pdf.

Executive Office of the President (EOP). 2021. Advancing racial equity and support for underserved communities through the federal government. Executive Order 13985. *Federal Register* 86, no. 14 (January 25): 7009–7013. https://www.federalregister.gov/ documents/2021/01/25/2021-01753/advancing-racial-equity-and-support-for-underserved-communities-through-the-federal-government.

Executive Office of the President, Office of Management and Budget (OMB). 2023. Initial proposals for updating OMB's race and ethnicity statistical standards. Notice

and request for comments. *Federal Register* 88, no. 18 (January 27): 5375–5384. https://www.federalregister.gov/documents/2023/01/27/2023-01635/initial-proposals-for-updating-ombs-race-and-ethnicity-statistical-standards.

Executive Office of the President, Office of Management and Budget (OMB). 2016. Standards for maintaining, collecting, and presenting federal data on race and ethnicity. Notice of proposed rulemaking. *Federal Register* 81, no. 190 (September 30): 67398–67401. https://www.federalregister.gov/documents/2016/09/30/2016-23672/standards-for-maintaining-collecting-and-presenting-federal-data-on-race-and-ethnicity.

Executive Office of the President, Office of Management and Budget (OMB). 1997. Revisions to the standards for the classification of federal data on race and ethnicity. Notice of decision. *Federal Register* 62, no. 210 (October 30): 58782–58790. https://www.federalregister.gov/documents/1997/10/30/97-28653/revisions-to-the-standards-for-the-classification-of-federal-data-on-race-and-ethnicity.

Executive Office of the President, Office of Management and Budget (OMB). 1977. *Race and ethnic standards for federal statistics and administrative reporting*. Directive No. 15. (May 12). https://transition.fcc.gov/Bureaus/OSEC/library/legislative_histories/1195.pdf.

Food and Nutrition Service (FNS), U.S. Department of Agriculture. 2005. *Civil rights compliance and enforcement—nutrition programs and activities*. Report no. 113-1. Alexandria, VA: U.S. Department of Agriculture. https://www.fns.usda.gov/fns-instruction-113-1.

Gilfoil, C.S. 2022. *Demographic data collection in Medicaid & CHIP: CMS authority to collect race & ethnicity data*. Washington, DC: National Health Law Program. https://healthlaw.org/wp-content/uploads/2022/09/Issue-Brief-Demo-Data-Medicaid-final.pdf.

James, C., S. Pamar, S. Hudson Scholle, et al. 2021a. *Improving data on race and ethnicity: A roadmap to measure and advance health equity*. Washington, DC: Grantmakers in Health. https://www.gih.org/wp-content/uploads/2021/12/GIH-Commonwealth-Fund-federal-data-report-part-2.pdf.

James, C., S. Pamar, S. Hudson Scholle, et al. 2021b. *Federal action is needed to improve race and ethnicity data in health programs*. Washington, DC: Grantmakers in Health. https://www.gih.org/wp-content/uploads/2021/10/GIH-Commonwealth-Fund-federal-data-report-part-1.pdf.

Labgold, K., S. Hamid, S. Shah, et al. 2021. Estimating the unknown: Greater racial and ethnic disparities in COVID-19 burden after accounting for missing race and ethnicity data. *Epidemiology* 32, no. 2: 157–161. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8641438/pdf/nihms-1754433.pdf.

LLanos, K., and L. Palmer. 2006. *Using data on race and ethnicity to improve health care quality for Medicaid beneficiaries*. Hamilton, New Jersey: Center for Health Care Strategies. http://www.chcs.org/media/Using_Date_to_Reduce_Health_Disparities.pdf.

Mathematica. 2023. E-mail with MACPAC, January 27.

Mathematica. 2022. E-mail with MACPAC, December 19.

Matthews, K., J. Phelan, N.A. Jones, et al. 2017. *2015 national content test race and ethnicity analysis report: A new design for the 21st century*. Washington, DC: U.S. Census Bureau. https://assets.documentcloud.org/documents/4316468/2015nct-Race-Ethnicity-Analysis.pdf.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2022a. Chapter 6: Medicaid's role in advancing health equity. In *Report to Congress on Medicaid and CHIP*. June 2022. Washington, DC: MACPAC. https://www.macpac.gov/wp-content/uploads/2022/06/Chapter-6-Medicaids-Role-in-Advancing-Health-Equity.pdf.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2022b. *Availability of race and ethnicity data for Medicaid beneficiaries*. Washington, DC: MACPAC. https://www.macpac.gov/publication/availability-of-race-and-ethnicity-data-for-medicaid-beneficiaries/.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2022c. Exhibit 1: Medicaid and CHIP enrollment as a percentage of the U.S. population, 2021 (millions). In *MACStats: Medicaid and CHIP Data Book*. December 2022. Washington, DC: MACPAC. https://www.macpac.gov/publication/medicaid-and-chip-enrollment-as-a-percentage-of-the-u-s-population/.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2022d. Exhibit 2: Characteristics of noninstitutionalized individuals by age and source of health coverage, 2021. In *MACStats: Medicaid and CHIP Data Book*. December 2022. Washington, DC: MACPAC. https://www.macpac.gov/publication/characteristics-of-non-institutionalized-individuals-by-source-of-health-insurance/.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2021a. *Racial and ethnic disparities in Medicaid: An annotated bibliography*. Washington, DC: MACPAC. https://www.macpac.gov/wp-content/uploads/2021/04/Racial-and-Ethnic-Disparities-in-Medicaid-An-Annotated-Bibliography.pdf.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2021b. *Update on Transformed Medicaid Statistical Information System (T-MSIS)*. Washington, DC: MACPAC. https://www.macpac.gov/wp-content/uploads/2021/04/Update-on-Transformed-Medicaid-Statistical-Information-System-T-MSIS.pdf.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2018. *Eligibility, enrollment, and renewal: Case study findings*. Washington, DC: MACPAC. https://www.macpac.gov/publication/eligibility-enrollment-and-renewal-case-study-findings/.

New York State of Health (NYSOH). 2021. *Cultural humility: NY State of Health race & ethnicity questions*. Albany, NY: NYSOH. https://info.nystateofhealth.ny.gov/sites/default/files/Cultural%20Humility%20and%20NYSOH%20Race%20and%20Ethnicity%20Questions.pdf.

North Carolina Department of Health and Human Services, Division of Public Health (NCDHHS). 2022. *North Carolina state health improvement plan*. Raleigh, NC: NCDHHS. https://schs.dph.ncdhhs.gov/units/ldas/docs/NCSHIP-2022-Full.pdf.

Ojodu, J., M.M. Hulihan, S.N. Pope, and A.M. Grant. 2014. Incidence of sickle cell trait—United States, 2010. *Morbidity and Mortality Weekly Report* 63, no. 49: 1155–1158. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4584538/.

Ortman, J.M., and K.L. Parker. 2021. *Why do federal agencies ask about sexual orientation and gender identity (SOGI) on surveys?* Report no. FCSM-21-01. Washington, DC: Federal Committee on Statistical Methodology. https://nces.ed.gov/FCSM/pdf/FCSM_21_01_062221.pdf.

Orvis, K. 2022. *Reviewing and revising standards for maintaining, collecting, and presenting federal data on race and ethnicity*. White House Briefing Room, June 15. https://www.whitehouse.gov/omb/briefing-room/2022/06/15/reviewing-and-revising-standards-for-maintaining-collecting-and-presenting-federal-data-on-race-and-ethnicity/.

Planalp, C. 2021. *New York State of Health pilot yields increased race and ethnicity question response rates*. Minneapolis, MN: State Health Access Data Assistance Center. https://www.shvs.org/new-york-state-of-health-pilot-yields-increased-race-and-ethnicity-question-response-rates/.

Pollitz, K., J. Tolbert, L. Hamel, and A. Kearney. 2020. *Consumer assistance in health insurance: Evidence of impact and unmet need*. Washington, DC: KFF. https://www.kff.org/report-section/consumer-assistance-in-health-insurance-evidence-of-impact-and-unmet-need-issue-brief/.

Research Data Assistance Center (ResDAC). 2022. Data documentation: TAF demographic and eligibility file. Minneapolis, MN: ResDAC. https://resdac.org/cms-data/files/taf-de/data-documentation.

Rubin, V., D. Ngo, Á. Ross, et al. 2018. *Counting a diverse nation: Disaggregating data on race and ethnicity to advance a culture of health*. Oakland, CA: PolicyLink. https://www.policylink.org/sites/default/files/Counting_a_Diverse_Nation_08_15_18.pdf.

Saunders, H., and P. Chidambaram. 2022. *Medicaid administrative data: Challenges with race, ethnicity, and other demographic variables*. Washington, DC: KFF. https://www.kff.org/medicaid/issue-brief/medicaid-administrative-data-challenges-with-race-ethnicity-and-other-demographic-variables/.

Sheedy, K. 2014. *Medicaid agency training for consumer assisters in Federally Facilitated Marketplace states*. Portland, ME: National Academy for State Health Policy. https://nationaldisabilitynavigator.org/wp-content/uploads/resources-links/Medicaid_Training_for_Assisters_in_FFM_States.pdf.

Sholle, E.T., L.C. Pinheiro, P. Adekkanattu, et al. 2019. Underserved populations with missing race ethnicity data differ significantly from those with structured race/ethnicity documentation. *Journal of the American Medical Informatics Association* 26, no. 8–9: 722–729. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6696506/pdf/ocz040.pdf.

State Health Access Data Assistance Center (SHADAC), University of Minnesota. 2022. *Collection of race, ethnicity, language (REL) data on Medicaid applications: New and updated information on Medicaid data collection practices in the states, territories, and District of Columbia*. Minneapolis, MN: SHADAC. https://www.shvs.org/wp-content/uploads/2022/11/SHVS_Collection-of-Race-Ethnicity-Language-REL-Data-on-Medicaid-Applications.pdf.

U.S. Department of Health and Human Services (HHS). 2022a. Health equity timeline. Washington, DC: HHS. https://thinkculturalhealth.hhs.gov/clas/health-equity-timeline.

U.S. Department of Health and Human Services (HHS). 2022b. *Imputation of race and ethnicity in health insurance marketplace enrollment data, 2015–2022 Open Enrollment Periods*. Washington, DC: HHS. https://aspe.hhs.gov/reports/imputation-race-ethnicity-marketplace-enrollment-data.

U.S. Department of Health and Human Services (HHS). 2022c. Interview with MACPAC, October 20.

U.S. Department of Health and Human Services (HHS). 2011a. *Implementation guidance on data collection standards for race, ethnicity, sex, primary language, and disability status*. Washington, DC: HHS. https://aspe.hhs.gov/sites/default/files/migrated_legacy_files//43681/index.pdf.

U.S. Department of Health and Human Services (HHS). 2011b. *Approaches for identifying, collecting and evaluating data on health care disparities in Medicaid and CHIP*. Washington, DC: HHS. https://www.medicaid.gov/medicaid/quality-of-care/downloads/4302b-rtc.pdf.

U.S. Department of Health and Human Services (HHS). 1997. *Policy statement on inclusion of race and ethnicity in DHHS data collection activities*. Washington, DC: HHS. https://aspe.hhs.gov/collaborations-committees-advisory-groups/hhs-data/hhs-data-council-introduction/dc-archive/policy-statement-inclusion-race-ethnicity-dhhs-data-collection-activities.

U.S. Government Accountability Office (GAO). 2020. *Medicaid information technology: Effective CMS oversight and states' sharing of claims processing and information retrieval systems can reduce costs*. Report no. GAO-20-179. Washington, DC: GAO. https://www.gao.gov/assets/gao-20-179.pdf.

Youdelman, M., and S. Hitov. 2001. *Racial, ethnic and primary language data collection: An assessment of federal policies, practices and perceptions*. Washington, DC: National Health Law Program. https://healthlaw.org/wp-content/uploads/2018/09/shire.report.pdf.

MACPAC

APPENDIX 1A: Data Collection Standards

TABLE 1A-1. Race and Ethnicity Data Collection Standards

1977 OMB minimum standards	1997 OMB minimum standards	2011 HHS guidance
Race Categories		
White	White	White
Black	Black or African American	Black or African American
Asian or Pacific Islander	Asian	Asian Indian
		Chinese
		Filipino
		Japanese
		Korean
		Vietnamese
		Other Asian
American Indian or Alaskan Native	American Indian or Alaska Native	American Indian or Alaska Native
	Native Hawaiian or Other Pacific Islander	Native Hawaiian
		Guamanian or Chamorro
		Samoan
		Other Pacific Islander
Ethnicity Categories		
Hispanic origin	Hispanic or Latino	Mexican, Mexican American, Chicano/a Puerto Rican Cuban Another Hispanic, Latino/a, or Spanish origin
Not of Hispanic origin	Not Hispanic or Latino	Not of Hispanic, Latino/a, or Spanish origin

Notes: OMB is Office of Management and Budget. HHS is U.S. Department of Health and Human Services.

Sources: HHS 2011; OMB 1997, 1977.

Commission Vote on Recommendations

In its authorizing language in the Social Security Act (42 USC 1396), Congress requires MACPAC to review Medicaid and CHIP program policies and make recommendations related to those policies to Congress, the Secretary of the U.S. Department of Health and Human Services, and the states in its reports to Congress, which are due by March 15 and June 15 of each year. Each Commissioner must vote on each recommendation, and the votes for each recommendation must be published in the reports. The recommendations included in this report, and the corresponding voting record below, fulfill this mandate.

Per the Commission's policies regarding conflicts of interest, the Commission's conflict of interest committee convened prior to the vote to review and discuss whether any conflicts existed relevant to the recommendations. It determined that, under the particularly, directly, predictably, and significantly standard that governs its deliberations, no Commissioner has an interest that presents a potential or actual conflict of interest.

The Commission voted on these recommendations on January 27, 2023.

_____

Medicaid Race and Ethnicity Data Collection and Reporting

1.1 The Secretary of the U.S. Department of Health and Human Services (HHS) should update the model single, streamlined application to include updated questions to gather race and ethnicity data. These questions should be developed using evidence-based approaches for collecting complete and accurate data. The updated application should include information about the purpose of the questions so that the applicant understands how this information may be used. HHS should also direct the Centers for Medicare & Medicaid Services to update guidance on how to implement these changes on a Secretary-approved application.

1.2 The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services to develop model training materials to be shared with state and county eligibility workers, application assisters, and navigators to ensure applicants receive consistent information about the purpose of the race and ethnicity questions. The training materials should be developed with the input of states, beneficiaries, advocates, and application assisters and navigators, user tested prior to implementation, and adaptable to state and assister needs.

1.1-1.2 voting results	#	Commissioner
Yes	16	Allen, Bella, Bjork, Brooks, Carter, Cerise, Davis, Duncan, Gerstorff, Giardino, Gordon, Heaphy, Johnson, Medows, Scanlon, Weno
Not present	1	Herrera Scott