January 26, 2023

Improving Medicaid Race and Ethnicity Data Collection and Reporting

Review of recommendations and draft chapter for March report

Linn Jennings and Jerry Mi







Chapter Outline

- Importance of high-quality race and ethnicity data
- Medicaid data collection and reporting
- Challenges and approaches to improving data quality
- Recommendations and rationale

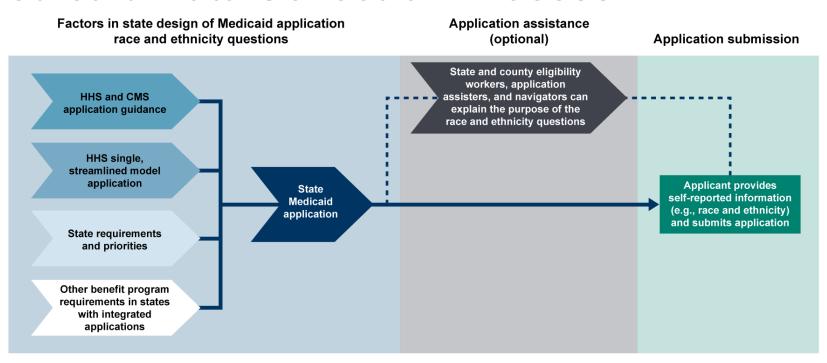


Importance of High-Quality Race and Ethnicity Data

- Racial and ethnic health disparities persist throughout the U.S. health care system
- High rates of missing race and ethnicity data may lead to a biased, inaccurate, and incomplete understanding of health disparities
- Improving health equity has long been a priority of the U.S.
 Department of Health and Human Services (HHS) and the Centers for Medicaid & Medicaid Services (CMS)
- Some states are also developing targeted policies to address disparities



Medicaid Data Collection Process

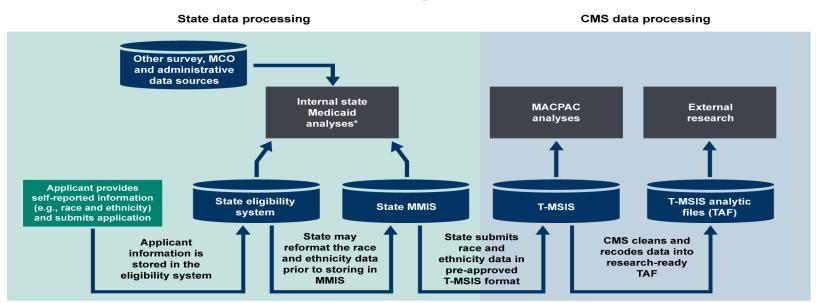


Notes: HHS is U.S. Department of Health and Human Services. CMS is Centers for Medicare & Medicaid Services.

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



Medicaid Data Reporting Process



Notes: MMIS is Medicaid Management Information System. T-MSIS is the Transformed Medicaid Statistical Information System. TAF is T-MSIS Analytical Files.

^{*} Some states supplement application data with other state data sources (e.g., managed care organization data) for internal analyses. However, these data never supplement or update the state eligibility system, state MMIS, or change the data submitted to T-MSIS.



Challenges with Improving Data Quality

Challenges with collecting and reporting these data may limit their completeness and accuracy

- Collection: Applicant concerns about how data may be used, fear
 of being denied coverage, and misunderstanding of the questions,
 especially when the categories do not align with their identity
- Reporting: Misalignment between how state eligibility systems, Medicaid Management Information Systems (MMIS), and Transformed Medicaid Statistical Information System (T-MSIS) store and format these data



Approaches to Improving Data Quality

Potential approaches to improving the usability of Medicaid race and ethnicity data:

- Update race and ethnicity application questions using evidencebased approaches to improve applicant willingness to respond
- Develop and provide training materials to help improve applicant trust in sharing their race and ethnicity

Draft Recommendations, Rationale, and Implications



Draft Recommendation 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.



Draft Recommendation 1: Rationale

- Implementing evidence-based approaches to asking race and ethnicity questions on the model application may improve applicant understanding and trust in providing sensitive information
- Updated guidance for states is also needed to support implementation since the majority of states developed alternative or modified applications



Draft Recommendation 1: Implications

Federal spending. Potential short-term increase as the new application is developed and implemented, including matching costs to the states for any associated systems changes

States. Application changes and system upgrades may be necessary, but to the extent that they align with ongoing work, the additional effort may be minimal

Enrollees. Greater applicant understanding and trust in responding to these questions may lead to program improvements due to higher data quality and the ability to assess and address disparities

Plans and providers. Unlikely to be directly affected by this recommendation



Draft Recommendation 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.



Draft Recommendation 2: Rationale

Providing state and county eligibility workers, application assisters, and navigators with training materials on how to ask applicants for race and ethnicity information would help address some of the challenges with collecting this information by:

- improving assister knowledge about why these questions are included and how the information may be used by the Medicaid program
- providing assisters with sample language to explain to applicants why this information is collected



Draft Recommendation 2: Implications

Federal spending. Potential short-term increase in federal costs as training materials are developed and implemented

States. Potential short-term costs for states that do not currently produce training materials and minimal effort to update existing state training materials

Enrollees. May lead to improved application assistance and understanding of the purpose of these data

Plans and providers. Could lead to improved ability for providers to assist applicants



Recommendation Summary

- Update HHS model application and guidance to states to improve applicant response rates
- Develop model training materials related to collecting race and ethnicity questions to increase applicant trust



Draft Recommendation 1

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Draft Recommendation 2

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January 27, 2023

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Vote on Recommendations for March Report

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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.



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.