The State of the Collection of Race, Ethnicity, and Language Data in Medicaid

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Health equity is of vital importance for federal, state, and local governments. This article describes the process states follow when obtaining information on race, ethnicity, and language spoken at home (REL) for their Medicaid beneficiaries; uses Transformed Medicaid Statistical Information System (T-MSIS) data from the Data Quality Atlas to identify fifteen states that have collected RE data on their beneficiaries over the years; summarizes state efforts to improve such data collection, including profiles of California, Washington state, Michigan, and Pennsylvania; and identifies lessons learned and recommendations for states to improve data collection that supports health equity initiatives.

Federal guidance from the Office of Management and Budget (OMB) do not mandate collection of race and ethnicity (RE) data for a Medicaid application; as a result, such reporting is optional. The comprehensiveness of state Medicaid data on REL can be assessed using the T-MSIS Data Quality Atlas, based on T-MSIS Analytic Files (TAF). Our review of data completeness and quality for three years (2017, 2018, and 2019) finds that most states were consistent over the three-year period in their level of concern.

Four states (California, Washington, Michigan, and Pennsylvania) were identified as Low Concern for collection of RE data in the DQ Atlas. Key features across the states include multiple formats for applications, extensive response options for REL (beyond the OMB categories), and state use of REL data on Medicaid beneficiaries to analyze health disparities and support programs to reduce such disparities. Other lessons learned included: ensuring alignment in questions and options across applications; encouraging applicants to self-report REL data; and linking collection of REL data to performance monitoring, contract requirements, and value-based payment.

Our study identifies several recommendations, as follows:

- States should publicly communicate how they plan to use REL data to advance health equity and reduce health disparities.
- We support the Grantmakers in Health and NCQA's recommendations for the OMB to update their race and ethnicity categorizations.
- We strongly recommend that states consider partnering to collect REL data, with health plans and health systems that deliver care to Medicaid beneficiaries.
- The federal government should provide technical assistance to states, to increase the comprehensiveness and accuracy of REL data.

Introduction

The pandemic has revealed significant inequities in health care for populations of different races and ethnicities. Health equity is of vital importance for federal, state, and local governments. This issue is currently a priority of the Biden administration and particularly the Centers for Medicare & Medicaid Services (CMS). Many state Medicaid agencies and local governments have been actively developing and implementing meaningful initiatives to advance health equity. However, one of the main challenges these entities face is the lack of information on individuals' race, ethnicity, or language (REL) spoken at home. Without data on REL, it is more challenging to identify and measure health inequities and health disparities. It is often said that what isn't measured can't be acted upon and improved. The objectives of this article are to:

1. Describe the process states follow when obtaining information on race, ethnicity, and language spoken at home for their Medicaid beneficiaries

2. Identify states that are consistently collecting race and ethnicity data for the majority of their beneficiaries over the years, from the Transformed Medicaid Statistical Information System (T-MSIS) data

3. Describe state efforts to improve the collection of race and ethnicity data, including profiles of efforts in California, Washington state, Michigan, and Pennsylvania

4. Identify lessons learned and recommendations for states to improve the collection of race and ethnicity data to support their health equity initiatives

Classification of Race, Ethnicity, and Language (REL) Data

Guidelines from the Office of Management and Budget (OMB) include how Medicaid classifies data and in turn, how Medicaid programs collect race and ethnicity data. Medicaid programs follow the Office of Management and Budget (OMB) 's recommendations and classifications for collecting data on race and ethnicity. The most recent standards from OMB were set in revisions to OMB Statistical Policy Directive No. 15, originally issued in 1977 and revised in 1997, which defined minimum standards for collecting and presenting race and ethnicity data for all Federal reporting, including Medicaid. Five racial categories were defined as American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or other Pacific Islander, and White, while ethnic categories were defined as Hispanic or Latino and Not Hispanic or Latino.[i] This was an expansion from the four racial categories noted in the 1977 directive, which combined Asian and Native Hawaiian/Other Pacific Islander and did not include the term "Latino" as part of the ethnicity question.[ii]

The Census Bureau offers a recent example of how to adhere to the OMB guidelines while modernizing the race and ethnicity categories to reflect the cultural diversity of the population. The Census Bureau has developed improvements to questions on race and ethnicity; testing on these improvements began in 2015, and the changes were made to the Census itself in 2020. Per 1997 OMB guidelines, race and ethnicity must be assessed in two separate questions. The 2020 Census revised the ethnicity question used in 2010, to include the three Hispanic origin options (Yes, Mexican, Mexican Am., Chicano; Yes, Puerto Rican; Yes, Cuban) as well as an additional "Yes, another Hispanic, Latino, or Spanish origin" option with revised language regarding the "print origin" direction, which allows respondents to self-identify their specific ethnicity if not listed. The list of example groups was further revised to reflect the largest Hispanic origin population groups, to eliminate confusion and improve the accuracy of self-reporting. The question on race was revised to include write-in sections under the White and Black or African American categories, with six example groups included for each (e.g., German, Irish, African American, Jamaican, Haitian), and the Asian category was split into seven specific categories including a write-in "other" option; similarly, Pacific Islander is split into 4 specific categories including a write-in "other" option.[iii]

State Collection of REL Data

Federal requirements define how state Medicaid agencies can collect REL information from beneficiaries. Federal guidelines do not mandate collection of race and ethnicity data for a Medicaid application, as outlined under Federal Regulation, 42 CFR § 435.907, which states, "the agency may only require an applicant to provide the information necessary to make an eligibility determination or for a purpose directly connected to the administration of the State plan." Racial and ethnic declarations are not required to make an eligibility determination for a state Medicaid plan; for this reason, these questions are not required to be answered as part of the application, though they must be presented in accordance with the 1997 Revised OMB Directive.[iv]

According to NORC's Framework for Advancing Health Equity in State Medicaid Programs, in general

> "State Medicaid Agencies (SMAs) ask Medicaid applicants about REL during the application process. However, states can only require applicants to report information needed to determine Medicaid eligibility, per federal requirements. Given that REL are not needed to determine Medicaid eligibility, SMAs often consider these fields optional, and applicants can leave them blank.[1] After becoming Medicaid eligible, members interact with the health plan they are enrolled in or with their health care providers more often than with the SMA."[v]

This could mean fewer opportunities for SMAs to collect REL data directly. Those states with low percentages of missing REL data may have key insights into strategies for successfully collecting such data.

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[1] Per 42 CFR 435.907(e), SMAs "may only require an applicant to provide the information necessary to make an eligibility determination": 42 CFR § 435.907 - Application. LII / Legal Information Institute. Accessed March 31, 2021. https://www.law.cornell.edu/cfr/text/42/435.907

Analysis of Quality of Race and Ethnicity (RE) Data by States in Data Quality Atlas (T-MSIS)

The comprehensiveness of REL data from state Medicaid agencies can be assessed using the T-MSIS Data Quality (DQ) Atlas, a valuable tool in measuring the completeness of race and ethnicity information present in the T-MSIS Analytic Files (TAF). The DQ Atlas uses data from TAF, which provides the most comprehensive country-wide data set on beneficiaries, providers, and service utilization, as well as other features of Medicaid and Children's Health Insurance Program (CHIP).[vi] The Atlas can be used to predict how well Medicaid RE data reported by states aligns with race and ethnicity data presented in the U.S. Census Bureau's American Community Survey (ACS). [2]

We conducted an in-depth review of the DQ Atlas during three data years (2017, 2018, and 2019) and identified differing patterns of reporting styles for RE data. The DQ Atlas assessed RE data quality on the following criteria: 1) the percentage of enrollment records with missing race and/or ethnicity values in TAF; and 2) how well the percentage of beneficiaries in each of the five race/ethnicity categories (White, non-Hispanic; Black, non-Hispanic; Asian, non-Hispanic; Hispanic, all races; All other races, non-Hispanic) aligned with data reported by the ACS. The DQ Atlas categorized their findings in the following way:

Low Concern ●

Percentage of enrollment records with less than 10% (≤ 10%) missing RE information and zero (0) RE categories where TAF data differ from ACS data by more than 10%

Medium Concern ●

Percentage of enrollment records with less than 10% (≤ 10%) missing RE information and one or two (1 or 2) RE categories where TAF data differ from ACS data by more than 10%

Percentage of enrollment records with more than 10% and less than 20% missing RE information (10% < X ≤ 20%) and zero or 1 (0 or 1) RE categories where TAF data differ from ACS data by more than 10%

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[2] For more information about the methodology used by the DQ Atlas to analyze the race and ethnicity data, please consult the background and methods resource in the following link: https://www.medicaid.gov/dq-atlas/downloads/background_and_methods/TAF_DQ_Race_Ethnicity.pdf

High Concern ●

Percentage of enrollment records with less than 10% (≤ 10%) missing RE information and three or more (3+) RE categories where TAF data differ from ACS data by more than 10%

Percentage of enrollment records with more than 10% and less than 20% missing RE information (10% < X ≤ 20%) and two or more (2+) RE categories where TAF data differ from ACS data by more than 10%

Percentage of enrollment records with more than 20% and less than 50% missing RE information (20%< X ≤ 50%) and has any RE categories where TAF data differ from ACS data by more than 10%

Unusable Data ●

Percentage of enrollment records with more than 50% (> 50%) missing RE information and any RE categories where TAF data differ from ACS data by more than 10%

Source: DQ Atlas Background and Methods Resource for the Race and Ethnicity Topic within the Beneficiary Information Topic Area

See Exhibit 1 and Exhibit 1a below for results. Our analysis excluded ten states (depicted in gray) where data quality did not remain in the same category between 2017 and 2019.

Exhibit 1. Depicts the states where data quality reporting remained within the same level of concern (Low Concern/Medium Concern/High Concern/Unusable) between 2017-2019.
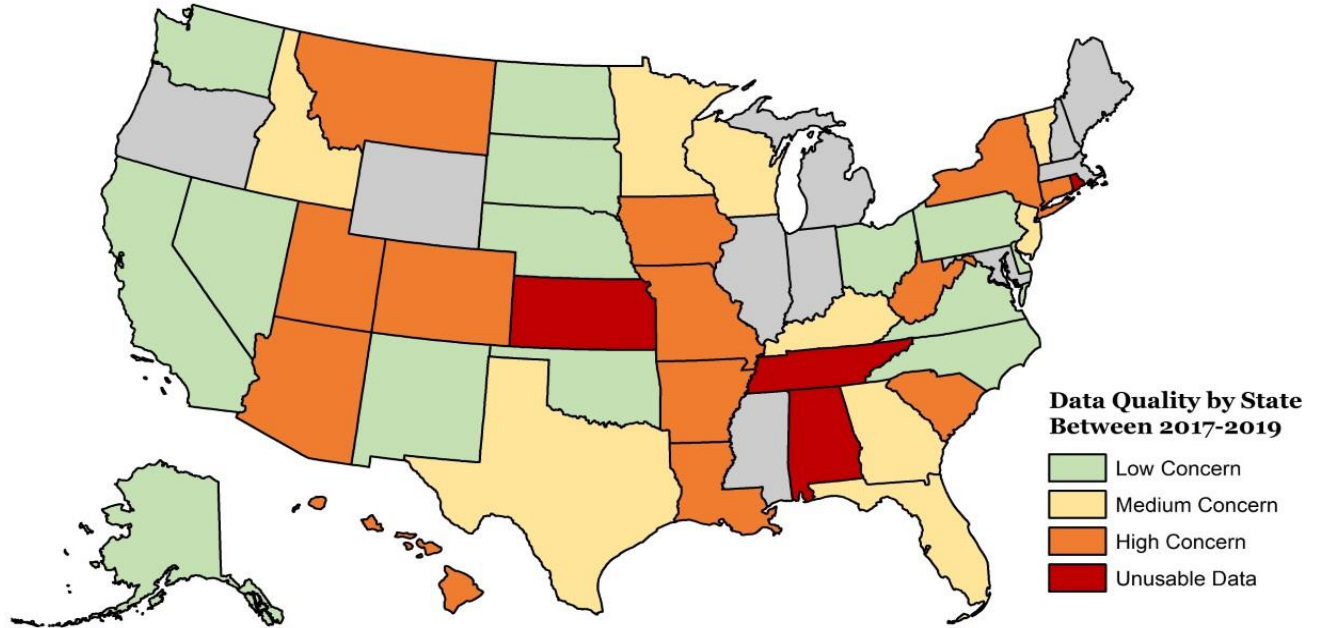
Source: DQ Atlas – DQ Assessments for Race and Ethnicity under Beneficiary Information

Exhibit 1a. States that maintained a consistent Level of Concern, based on the T-MSIS Analytic Files criteria of data completeness

Remained A Low Concern in DQ Atlas Between 2017-2019 (Green)	Remained a Medium Concern in DQ Atlas Between 2017-2019 (Yellow)	Remained a High Concern in DQ Atlas Between 2017-2019 (Orange)	States That Continued to Report Unusable Data According to DQ Atlas Between 2017-2019 (Red)
Alaska	Florida	Arizona	Alabama
California	Georgia	Arkansas	Kansas
Delaware	Idaho	Colorado	Rhode Island
Nebraska	Kentucky	Connecticut	Tennessee
Nevada	Minnesota	District of Columbia	
New Mexico	New Jersey	Hawaii	
North Carolina	Texas	Iowa	
North Dakota	Vermont	Louisiana	
Ohio	Wisconsin	Missouri	
Oklahoma		Montana	
Pennsylvania		New York	
South Dakota		South Carolina	
Virginia		Utah	
Washington		West Virginia	

Source: DQ Atlas – DQ Assessments for Race and Ethnicity under Beneficiary Information

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Note: For Exhibits 1 and 1a, the colors align with the *DQ Atlas* legend on *Medicaid.gov*

- 🟢 Low Concern
- 🟡 Medium Concern
- 🟠 High Concern
- 🔴 Unusable

Most states that reported data to T-MSIS fell into the Low Concern and High Concern categories of data quality. Geography does not appear to correlate with data quality. However, state-specific policies around data collection and reporting of RE data to T-MSIS may provide insights into how states remained in the same data quality category for a continuous three-year span. Additionally, further research into the four states that reported data deemed unusable by T-MSIS may yield valuable insight. Alabama, Kansas, Rhode Island, and Tennessee vary in demographics, politics, and health care landscapes. Identifying contributors to their data quality could improve future RE data collection from beneficiaries.

Several states showed change in reported data quality over the three consecutive years. Exhibit 2 shows three states (Illinois, Indiana, and Maine) reporting data of Low Concern in 2017 and 2018, followed by a decline in data quality to Medium Concern in 2019. Oregon and Wyoming both reported DQ that declined from Medium Concern to High Concern and remained as High Concern for two consecutive years.

Exhibit 2. Nine states showed a decline in reported DQ between 2017 and 2019.

States with a Decline in Data Quality Between 2017-2019	Pattern Description
Illinois	Low concern (2017, 2018) ● → Medium concern (2019) ●
Indiana	Low concern (2017, 2018) ● → Medium concern (2019) ●
Maine	Low concern (2017, 2018) ● → Medium concern (2019) ●
Maryland	Medium concern (2017, 2018) ● → High concern (2019) ●
Massachusetts	High concern (2017, 2018) ● → Unusable data (2019) ●
Mississippi	Low concern (2017) ● → Medium concern (2018, 2019) ●
New Hampshire	Low concern (2017) ● → Medium concern (2018, 2019) ●
Oregon	Medium concern (2017) ● → High concern (2018, 2019) ●
Wyoming	Medium concern (2017) ● → High concern (2018, 2019) ●

Exhibit 3 shows that there was a major data quality shift in Michigan, where reported data quality seemingly improved from High Concern to Low Concern within one year.

Exhibit 3. Michigan was the only state that reported improved data quality between 2017 and 2019.

State with Increase in Data Quality Between 2017-2019	Pattern Description
Michigan	High concern (2017,2018) ● → Low concern (2019) ●

Looking closer at data collection in the states listed in exhibits 2 and 3 could help us identify different state-specific models and methodologies of Medicaid beneficiary data collection and establish potential correlations between policy changes that could have contributed to these changes.

Implications of the Data

We have identified trends that merit further analysis. Future research could identify challenges that states face in statewide RE data collection from beneficiaries, as well as in how states submit RE data to T-MSIS. States are expected to report information on RE to T-MSIS; however, some states may not submit complete information because of challenges in data collection or technical difficulties in reporting. One reason for lack of complete RE data may be OMB guidance that establishes self-identification as the preferred means of obtaining RE information, and some beneficiaries choose not to disclose such data. The lack of complete RE data may be randomly distributed across a state's population or concentrated among certain racial and ethnic groups, presenting potential analytic

challenges such as reduced statistical power, weakened generalizability of findings, and possible bias in parameter estimation when conducting comprehensive analyses.

State Profiles with High Percentage of RE Data

Our analysis identified four states—California, Washington, Michigan, and Pennsylvania—as being Low Concern in collecting RE data according to the DQ Atlas. In this section, we identify key features across the four states that constitute successful REL data collection and highlight ways in which these four states apply REL data to advance health equity and related initiatives.[3] Obtaining quality REL data is key to assessing and addressing health-related inequities. Successful collection of REL data is a prerequisite to achieve programmatic and policy-oriented goals aimed at advancing health equity.

Methodology

Our state selection process included two steps. First, we used the Medicaid DQ Atlas, a publicly available resource available on Medicaid.gov, to assess the quality of Medicaid data across states, filtering for states identified as Low Concern for RE data collection activities.[vii] The DQ Atlas methodology identifies states as Low Concern if the race and ethnicity categories included in the TAF did not differ by more than 10 percent from the American Community Survey data for corresponding categories.[viii] Data for 2019 were used to identify Low Concern states, as complete updated data has yet to be published for 2020 and 2021. Fifteen states were recognized as Low Concern as of 2019. Some 2020 data was available for other categories of analysis and was used where available.

We then explored variation across the states regarding REL data collection processes and outcomes. To assess REL data collection processes, we reviewed states' paper and online Medicaid applications, paying particular attention to the number and specificity of RE response options. We considered the number of language options offered and whether applicants are asked to provide answers for both spoken and written language preferences. Additionally, we examined states' Medicaid websites and application portals to determine whether applications and related instructional resources are available in multiple languages, and whether translation or interpretation services are offered or advertised for beneficiaries. To assess RE data collection outcomes, we used the DQ Atlas data to identify the percentage of beneficiaries with missing race/ethnicity values in the TAF.

Our analysis also explored applications of REL data (for example, states using REL data to advance health equity-related programs) and trends in REL data collection (e.g., states identified as High Concern in 2018 that improved to Low Concern in 2019). We reviewed state Medicaid websites, as well as DQ Atlas data for the years before 2019. We supplemented our analysis by reviewing selected academic and grey literature. Once we completed our review of the fifteen Low Concern states, we

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[3] Please note that although we are highlighting four states that were identified as being low concern in collecting race and ethnicity (RE) data collection according to the DQ Atlas, we are exploring race, ethnicity, and **language** (REL) data collection processes and outcomes for the four selected states.

selected four states for profiles. Each of the four states exhibited particularly effective REL data collection and either noteworthy applications or trends in the quality of data collection activities. In selecting the four states to profile, we tried to select states that varied in terms of geographic location and demographic profile.

California

As of 2020, RE data were available in the TAF for 90 percent of California Medicaid beneficiaries. For reference, New York, which has the second largest Medicaid population after California, is missing race and ethnicity data for nearly a third of its Medicaid beneficiaries.[ix] [x] California has aimed to capture quality RE data to accurately reflect the diverse racial and ethnic makeup of the state's Medicaid population. California's paper and online Medicaid applications include sixteen response options for race, tied for the fifth most across all states.[xi] California also offers an extensive list of ethnicity response options. Some states do not offer any ethnicity options or limit their selection to only a couple of categories (e.g., Hispanic, non-Hispanic). In contrast, California's application includes country-of-origin-specific options (e.g., Guatemalan and Salvadorian) as well as more granular options such as Chicano/a; on the application, respondents are instructed to select all race and ethnicity options that apply.

To supplement information on race and ethnicity, California collects language data on their Medicaid population. Both the state's paper and online applications ask applicants about their preferred language for communication—both written and spoken. Additionally, the paper application as well as the Covered California website are available in twelve languages (English, Arabic, Armenian, Chinese, Farsi, Hmong, Khmer, Korean, Russian, Spanish, Tagalog, and Vietnamese), enhancing access to Medicaid registration and program resources.

Application of REL Data in California

California's promotion of health equity extends beyond the collection of REL data. The California Department of Health (DHCS) uses Medicaid REL data in reports and dashboards that identify and describe health-related inequities that affect their Medicaid population.[xii] Medicaid REL data are also used to generate publicly available, de-identified data files that allow analysis that stratifies by characteristics including race and ethnicity, to look at health disparities.[xiii]

Medicaid beneficiary REL data supports the creation of research- and policy-relevant resources. In addition, REL data is fundamental to the California Advancing and Innovating Medi-Cal (CalAIM) initiative, a statewide effort to improve the quality of life and health outcomes of California Medicaid beneficiaries through comprehensive delivery system, programmatic, and payment reforms.[xiv] DHCS has identified a central goal of CalAIM to be addressing social drivers of health and structural inequities that disproportionately impact California's Black and Latin communities.[xv]

The sheer number of Medicaid beneficiaries that California serves, and the socioeconomic, racial, and geographic diversity of its Medicaid population, mean that California offers a microcosm of the nation at large and a model for larger states on REL data collection and health equity promotion.

Washington

As of 2020, RE data were available in the TAF for 92.1 percent of Washington Medicaid, or Apple Health, beneficiaries, representing a slight increase from 91.6 percent in 2019. Apple Health provides several formats through which an individual can apply for or renew coverage: online, mobile application, phone, paper, or in-person.[xvi]

NORC reviewed the paper application on the Washington State Health Care Authority (HCA) website. This application collects race and ethnicity in an optional box where the applicant can check all that apply of the following seven response options: White, Black or African American, Asian, Native Hawaiian, Pacific Islander, Hispanic or Latino, and/or Other. If the applicant notes their option as American Indian or Alaska Native, they are directed to not enter a race or ethnicity and to instead respond YES or NO to the box below that asks, "Are you an American Indian or Alaska Native?" The application also includes a "Language Information" box where they can request an interpreter and receive documents in a language other than English. If the applicant needs the form in a different language or format, they can list all languages or formats that apply and may call to receive help in their language. Additionally, the applicant can provide race and ethnicity information or different language application/interpreter requests for others they are applying for, such as a spouse or dependent.

The online application is accessed through the Washington Healthplanfinder website by creating an account, which can also be used to access the "WAPlanFinder" mobile application. The online application's approach to collecting race and ethnicity is slightly different than the paper application, as the online application collects race and ethnicity separately. The first page collects demographics and explains why this is collected, which the application states is to "help improve health equity and increase access to health care for all individuals." Additionally, it advises the applicant that this information will not prevent them from enrollment. A series of questions follows:

- The first optional question is whether the applicant is of Hispanic, Latino, or Spanish origin. The following options may be selected: Cuban, Mexican/Mexican-American/Chicano, Not Spanish/Hispanic, Other Spanish/Hispanic, and Puerto Rican.
- A question about race is also optional. The applicant is provided 17 response options and can select up to four races, as follows: American Indian/Alaskan Native, Asian Indian, Black/African American, Cambodian, Chinese, Filipino, Guamanian, Hawaiian, Japanese, Korean, Laotian, Other Asian/Pacific Islander, Other Race, Samoan, Thai, Vietnamese, and White.
- A final question is required, requesting that the applicant answer the question "Are you an American Indian or Alaska Native" with YES and NO response options.

The application also includes a "Language Preferences" section, which collects similar information to the paper application.

Application of REL Data in Washington

Washington has a Healthier Washington (HW) Measures Dashboard, a set of interactive dashboards that uses filters to explore data on populations and measures for the state; the dashboards are updated on a quarterly basis.[xvii] One main data source for the dashboards is ProviderOne[4] Medicaid clams and enrollment data. [xviii] The filters on this dashboard include, but are not limited to, race, ethnicity, and language, which are pulled from Medicaid enrollment files. RE data come from ProviderOne enrollment files and individual self-reporting, while language is from "self-reported preferred spoken language."[xix] The dashboards display inclusive and exclusive RE groupings, as follows:

- For inclusive RE, the beneficiaries are counted towards each race and ethnicity category they select. The following are the inclusive groups: American Indian/Alaskan Native, Asian, Black, Hispanic/Latino, Native Hawaiian/Pacific Islander, White, Other, and Unknown.[xx]
- The exclusive RE grouping counts beneficiaries in a single race category, using the race selection entered in the first race field in ProviderOne. The following are the exclusive groups: Non-Hispanic White (selected a single race "white" and does not select Hispanic), Any Minority (selected Hispanic ethnicity, and/or reports a race category other than "white"), and Unknown (did not identify any ethnicity or at least on racial category).[xxi]

The interactive dashboards include:

- <u>Measure Explorer & Trend</u>: This dashboard displays "measure rates for Medicaid enrollees by geographic region and demographics."xxii Demographics and filters can be combined to see measure rates for specific populations. xxiii The user can filter by measure type (access, coordination, quality, social, surveillance, and utilization), measure name (e.g., acute hospital utilization, follow-up after hospitalization for mental illness: 7 days, mental health treatment penetration), region, age group, gender, language, race type (inclusive or exclusive), and race name.
- <u>Transformation Measures</u>: This dashboard allows users to explore "Accountable Communities of Health (ACHs) performance for groups of pay-for-performance (P4P) measures associated with the state's Medicaid Transformation Project (MTP) areas."xxiv MTP is Washington's Section 1115 Medicaid demonstration waiver between the Health Care Authority, which purchases Apple Health for Washington residents, and CMS, that is focused on ways to improve the state's health care system.xxv The dashboard can be filtered by project, region, and measurement year. The projects on this dashboard are as follows: Project 2A (Bi-directional Integration of Physical & Behavioral Health); Project 2B (Community-Based Care Coordination); Project 2C (Transitional Care); Project 2D (Diversion Interventions); Project 3A (Addressing the Opioid Use Public Health Crisis); Project 3B (Reproductive & Maternal/Child Health); Project 3C (Access to Oral Health Services); Project 3D (Chronic Disease Prevention & Control, and Statewide Accountability Measures). Each project has

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[4] The ProviderOne interface enables the exchange of information between the Automated Client Eligibility System (ACES) and the Health Care Authority (HCA) ProviderOne system. ProviderOne uses this information to authorize payment for medical bills from medical providers, to generate reports, and to obtain federal funding. (Website: https://www.dshs.wa.gov/esa/interface-data/providerone)

"project measures" (such as Acute Hospital Utilization per 1000 Members or Asthma Medication Ratio: Age 5-64 Years) and "measures" (rate) that can be selected and the dashboard then displays the rates at which the measure occurred for Medicaid members. Measures may also be viewed by race/ethnicity (exclusive and inclusive), county, language, and gender.[xxvi]

Michigan

As of 2020, RE data were available in the TAF for 91.8 percent of Michigan Medicaid beneficiaries, representing a significant increase from 6.6 percent in 2018.[xxvii] It is likely that the state has been collecting RE data for years, as Michigan has released health equity reports annually since 2011 and in 2019, began reporting it to the federal government.[5] The state collects race/ethnicity data during Medicaid enrollment through its paper application. Michigan also has a new online Medicaid application portal—MI Bridges. NORC was unable to access the online application, so it is unclear whether the state collects REL data through the online application

The paper application uses five response options for race (White; African American/Black; Asian; American Indian/Alaska Native; Native Hawaiian/Other Pacific Islander) and two categories for ethnicity (Hispanic/Latino; Not Hispanic Latino). The application also includes the following instructions for populating race/ethnicity data: "ethnicity/race is optional and will not affect eligibility. See Info Booklet for more details."[xxviii] Michigan's paper application includes an open-ended response option for "what language do you prefer" for both spoken language and written language. Additionally, the Michigan Department of Health and Human Services (MDHHS) landing page includes an option at the bottom for Language Assistance Services, with a phone number (and instructions in 15 languages) to call for free language assistance services.

Application of REL Data in Michigan

Michigan produces annual health equity reports to track health equity outcomes. Since 2012, MDHHS has included 13 Healthcare Effectiveness Data and Information Data HEDIS® measures stratified by race and ethnicity in their report. This approach—stratifying quality measure data by race and ethnicity data over time—makes Michigan unique compared with most states.[xxix] Reviewing data over time shows that African Americans have had lower rates than Whites for 10 of the 13 quality reporting measures, for every year since 2011. The Michigan health equity report in 2018 included a description of multiple ways that the state planned to address health disparities, including a three-year performance improvement project to reduce racial/ethnicity disparities in low-birth rate for Medicaid managed care recipients. The 2019 managed care contract also included a performance bonus for improving rates for certain race/ethnicity categories across five measures (HbA1c testing, cervical cancer screening, well-child visits, postpartum care, and chlamydia screening).[xxx]

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[5] To understand why Michigan was not sending their race and ethnicity data to the federal government prior to 2019, NORC suggests conducting phone interviews with the state in 2022.

Pennsylvania

As of 2020, RE data were available in the TAF for 93.3 percent of Pennsylvania Medicaid beneficiaries.[xxxi] Pennsylvania collects race/ethnicity data during Medicaid enrollment through both a paper and online application. The paper application uses six response options for race (White; Black or African American; Asian; American Indian/Alaskan Native; Native Hawaiian or Pacific Islander; Other), while the online application includes the same response options as the paper application plus an "unknown option." Both the paper and online applications include two categories for ethnicity (Hispanic/Latino; Not Hispanic Latino).[xxxii]

Pennsylvania's paper application includes a question for preferred language with the following options: English/Ingles, Spanish/Español, and Other. The "Other" category includes an open-ended response option. Notably, the Pennsylvania Medicaid application also asks "do you need an interpreter" in both Spanish and English. The response options are "Yes/Si" and "No" and "if yes, what language." At the top of the paper application is a notification that states, "if you need this application in another language or someone to interpret, please contact your local county assistance office. Language assistance will be provided free of charge."[xxxiii]

Application of REL Data in Pennsylvania

The Pennsylvania Office of Medical Assistance Programs (OMAP) has extensive experience measuring and analyzing racial and ethnic disparities and in sharing that data with managed care organizations (MCOs). To address health disparities, OMAP began linking 10 percent of the 2021 MCO P4P payments to improved health outcomes in the African American population. This requirement began with an incremental improvement payout for improved maternity and well-child measures for care delivered in 2020. Starting in 2022, OMAP will evaluate racial and ethnic disparities across measures and determine if additional measures should be added to the P4P program.[xxxiv]

Also in 2019, OMAP added language to MCO agreements that require either achieving or working toward receiving NCQA distinction in Multicultural Health Care. Distinction in Multicultural Health care recognizes MCOs that adhere to best practices for collecting REL data, providing language assistance, ensuring cultural responsiveness, and reducing health disparities. Pennsylvania is home to the first MCO in the country to achieve the designation, and the state now has a total of six MCOs with distinction in Multicultural Health Care. According to the 2020 Managed Care Quality Strategy Report, the Pennsylvania Department of Health Services (DHS) is considering expanding the requirement across all program offices that contract with MCOs. Finally, the Office of Mental Health and Substance Abuse Services (OMHSAS) recently began analyzing HEDIS® measure data stratified by a variety of demographics including race, ethnicity, gender, and geographic location. The results of these stratified measures are shared with the primary contractors and behavioral health MCOs.[6]

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[6] https://www.dhs.pa.gov/HealthChoices/HC-Services/Documents/Medical%20Assistance%20Quality%20Strategy%20for%20Pennsylvania.pdf

Lessons Learned from States with High Percentage of REL Data

We identified six common characteristics among the four states analyzed, that other states could replicate to improve the comprehensiveness of their REL data:

- **Conducting Medicaid applications in a variety of ways, including online, mail, and/or in-person**. Offering multiple ways to apply for Medicaid enables states to be more inclusive, ensuring that individuals from different races and ethnicities have more opportunities to apply for Medicaid benefits.

- **Ensuring alignment in the questions and options of the Medicaid eligibility applications.** In some instances, REL categories differed between a state's Medicaid paper and online applications. Alignment in response options will make it easier for the state to consolidate REL responses from different types of applications into their Medicaid Enterprise Systems (MES).

- **Encouraging applicants to self-report REL data, even though if not required to determine Medicaid eligibility.** At least one state, Washington, includes language in their application to encourage individuals to disclose REL data, by explaining how it will advance health equity and reduce disparities in the Medicaid program. Including language encouraging applicants to self-report REL data, and explaining how states will utilize the REL data in the Medicaid application, is a best practice that other states can adopt to increase self-reporting of REL information. Under federal law, race and ethnicity data is not required to make a Medicaid eligibility determination and is not required for a complete application. For this reason, states must devise strategies that encourage this voluntary reporting.

- **Expanding the number of race and ethnicity categories in the Medicaid application beyond the OMB categories.** All states offer more categorical options for reporting race and ethnicity than those outlined in the most recent OMB directive, last revised in 1997. California offers significantly more categories than the OMB, including 16 categories for race and country of origin (under ethnicity), and Washington state offers 17 different categories under race. Pennsylvania has fewer categories than do California and Washington, but Pennsylvania's categories are still more comprehensive than OMB guidelines. There is much that could be incorporated or adapted from individual state efforts.

- **Offering the Medicaid application in multiple languages.** Three states offer Medicaid applications in multiple languages (California offers the application in twelve different languages) and include an option for speaking with a translator in the language of their choice (Washington State, Pennsylvania). Increasing the number of languages for Medicaid applications allows states to take a more inclusive approach and support a more diverse pool of individuals applying for Medicaid benefits.

- **Linking the collection of REL data to performance monitoring, contract requirements, or value-based payment (VBP).** The four states used REL data to stratify quality measures included in public dashboards (California, Washington State, Michigan) or to assess if MCOs met performance targets in VBP arrangements (California, Pennsylvania). Michigan's annual health equity report is unique and a best practice that other states should follow. Since Michigan has been producing this report since 2012, the state can use Medicaid RE data to track health disparities for certain HEDIS® measures over time and use those findings to develop targeted health equity initiatives. Pennsylvania's approach centers on advancing health equity by having a 10 percent P4P requirement to improve health outcomes of African American communities. In addition, Pennsylvania requires their MCOs to obtain NCQA's Multicultural Distinction and may expand this requirement to other partners.

Additional Policy Recommendations and Considerations

The purpose of our analysis was to: 1) understand how states collect REL data from their beneficiaries; 2) examine the comprehensiveness of state REL data collected using the T-MSIS Data Quality Atlas; 3) identify states with a high percentage of RE data for their Medicaid members; and 4) describe factors that make these states successful at collecting REL data for their beneficiaries.

In the first sections of this paper, we described the process states use to collect REL data, which relies on individuals self-reporting the information as part of the Medicaid application. Per federal requirements, states cannot require applicants to provide the information. Therefore, we recommend states partner with member advocates and other organizations representing different racial and ethnic groups in their geographic areas to **encourage applicants to disclose REL information**. We also urge states to **publicly communicate how they plan to use REL data** as part of their efforts to advance health equity and reduce health disparities in their Medicaid programs, to encourage more self-reporting of REL data. These are recommendations that the Grantmakers in Health and NCQA make in their article "Federal Action is Needed to Improve Race and Ethnicity Data in Health Programs". [xxxv]

Another challenge to state collection is use of OMB guidelines on categorizing race and ethnicity that are outdated. Our analysis shows that states are expanding the number of reporting categories to reflect more accurately the diversity of their populations. Therefore, **we support the Grantmakers in Health and NCQA's recommendations for the OMB to update their race and ethnicity categorizations**. [xxxvi]

Additionally, we strongly recommend states consider partnering to collect REL data, with health plans and health systems delivering care for their Medicaid beneficiaries. Reliance on REL data collection at the time of Medicaid application results in a significant limitation. States can leverage a holistic view and take advantage of their beneficiaries' multiple interactions with health plans and health systems to

collect REL data. For this approach to be successful, states must establish strong partnerships with health plans and health systems. At the same time, states should have an inclusive stakeholder engagement process with member advocates, organizations representing different racial and ethnic populations, immigrants, and the community, for accountability. Member advocates and other organizations will ensure REL data is collected and shared by the state and its partners in a way that respects the beneficiaries' privacy, toward the goal of using REL data effectively to advance health equity and reduce disparities in Medicaid programs.

Our analysis of race and ethnicity data in T-MSIS through the DQ Atlas demonstrates that most states report RE data that is either in the Low Concern or High Concern categories; over time, states tend to remain within the same category of concern with only ten states changing categories over the three years analyzed. Our analysis did not show any geographic patterns or trends that could explain why some states fell into different categories of concern or why a very small group of states repeatedly reported unusable data.

Based on our analysis, we selected four states that had Low Concern about RE data collection. These states have made RE collection a priority over the years, and our analysis identified best practices from the four states. We note two limitations of our analysis. The first is that it is based on sources from the peer reviewed literature and information publicly available on state websites. The second is that the link between REL data and health equity initiatives is not always made clear on state Medicaid websites. For example, although collection of REL data allows for racially stratified analyses of a state's Medicaid population, few state Medicaid websites present such an analysis. In future research, we would like to interview Medicaid staff in these states, to better understand motivation to prioritize the collection of quality REL data and ways that such data are being used. Interviews with Medicaid staff may identify challenges associated with REL data collection and steps that states have taken to overcome such challenges. Findings from the interviews will be invaluable to other states facing similar issues and may help clarify the range of categories of concern across states.

Lastly, we recommend the federal government provides technical assistance to states to increase the comprehensiveness and accuracy of REL data. The Biden administration has made a commitment to making health equity one of the strategic pillars of CMS. Ensuring states have accurate and comprehensive REL data on their Medicaid beneficiaries will be the first step in that direction. Through technical assistance, the federal government would be able to learn directly from states about their challenges. In addition, federal officials may be in a better position to offer flexibility or additional funding to address such challenges, for example, by identifying ways for states to collect REL data or to modify their Medicaid eligibility application processes, to encourage more self-reporting of REL data.

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