



## Demographic Data Collection in Medicaid & CHIP: CMS Authority to Collect Race & Ethnicity Data

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CMS must collect comprehensive demographic information on Medicaid and Children's Health Insurance Program (CHIP) enrollees to understand whether these programs provide equitable care. Yet, demographic data collection throughout Medicaid and CHIP can lack consistency, uniformity and transparency. Many state agencies report missing, mismatched, or unavailable data. And much of the information collected remains inaccessible to the public, including to enrollees themselves.

CMS has a mandate to engage in comprehensive demographic data collection in the Medicaid and CHIP programs. Beginning in 1997, the Office of Management and Budget established minimum standards for collection of race and ethnicity data in federal statistical programs, including CMS programs. HHS has also required each of its projects and programs to engage in demographic data collection. However, in spite of these requirements, CMS has never required states to collect enrollee demographic information in a uniform manner.

**We recommend CMS issue guidance to states to help them improve their demographic data collection and hold them accountable to collecting demographic data in Medicaid and CHIP.** Although all states now collect and report some race and ethnicity information from enrollees, CMS has never formally stated its expectations for state Medicaid programs to engage in demographic data collection, particularly on applications, in regulations or guidance. CMS should adopt HHS' 2011 data standards and provide funding, resources and technical assistance to states to implement data collection activities. This would enable CMS and states to better address health disparities, advance culturally and linguistically appropriate care, facilitate accountable equity plans, and monitor civil rights compliance.

### A History of Demographic Data Requirements

The current federal standards for collecting information on race and ethnicity were first promulgated by the Office of Management and Budget (OMB) in 1977. The standards, published in the Federal Register as "Directive No. 15," were meant to govern the

“recordkeeping, collection, and presentation of data on race and ethnicity in Federal program administrative reporting and statistical activities.”<sup>1</sup> Directive No. 15 sets out specific minimum race and ethnicity variables that must be used if a federal program chooses to collect information on the race and ethnicity of participants.<sup>2</sup> However, it does not require all federal statistical programs to collect information on the race and ethnicity of program participants.<sup>3</sup>

OMB promulgated Directive No. 15 for the purpose of creating uniformity in demographic data collection across federal programs. OMB particularly intended Directive No. 15 standards to be used in civil rights compliance reporting, recordkeeping, grant reporting, and statistical reporting.<sup>4</sup> OMB also emphasized the importance of demographic data collection for monitoring and enforcing individual civil rights, equal access in housing, education, employment, and other public accommodations.<sup>5</sup>

OMB’s initial racial and ethnic reporting requirements specified use of the following racial and ethnic variables to collect data: American Indian or Alaskan Native; Asian or Pacific Islander; Black; Hispanic; and White.<sup>6</sup> In 1997, OMB published an updated version of Directive No. 15 that changed the race variables to American Indian or Alaska Native; Asian; Black or African American; Native Hawaiian or Other Pacific Islander; and White.<sup>7</sup> OMB created a separate ethnicity category for which there are only two variables: Hispanic and Not Hispanic.<sup>8</sup> OMB has not updated Directive No. 15 since 1997 but plans to do so in the next two years.<sup>9</sup>

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<sup>1</sup> 43 Fed. Reg. 19269 (May 4, 1978).

<sup>2</sup> *Id.* The word “variables” is used throughout this memo to refer to the named races and ethnicities in the Directive No. 15 standards (i.e., “Hispanic,” “Black/African American,” “Native Hawaiian,” etc.). The word “categories” is used to refer to the type of demographic data collected (i.e., “race,” “ethnicity”).

<sup>3</sup> 62 Fed. Reg. 58788 (Oct. 30, 1997).

<sup>4</sup> 43 Fed. Reg. 19269-19270 (May 4, 1978).

<sup>5</sup> “Development of the data standards stemmed in large measure from new responsibilities to enforce civil rights laws.” 62 Fed. Reg. 58782 (Oct. 30, 1997).

<sup>6</sup> 43 Fed. Reg. 19269 (May 4, 1978).

<sup>7</sup> 62 Fed. Reg. 58789 (October 30, 1997).

<sup>8</sup> *Id.*

<sup>9</sup> *But see* Karin Orvis, *Reviewing and Revising Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity*, THE WHITE HOUSE: BRIEFING ROOM BLOG (Jun. 15, 2022), <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/>. In

## OMB's Directive No. 15 Sets the Minimum Standards for Demographic Data Collection on Race and Ethnicity by CMS

Although never directly stated by OMB, Directive No. 15 applies to demographic data collection conducted by CMS. OMB's Directive No. 15 governs the data collection activities of federal statistical agencies and statistical programs.<sup>10</sup> A statistical program is any program within an agency that conducts statistical activities, such as program evaluation, research, data collection, or policy and program analysis.<sup>11</sup> Statistical activities include "collection, compilation, processing, analysis, or dissemination of data for the purpose of describing or making estimates concerning the whole."<sup>12</sup>

By the above definition, CMS conducts statistical activities within the definition given by OMB. CMS's statistical activities include measurement of the following:

the beneficiary population and subgroups; characteristics of providers of services; person-based utilization data; service location utilization data; procedure-specific data for physicians and suppliers; longitudinal data on beneficiaries, characteristics, and service utilization; and tabulations of financial and statistical data from all Medicaid-certified hospitals and hospital and health care complexes.<sup>13</sup>

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2022, OMB initiated a process by which it will review and revise the standards in Directive No. 15 to "better reflect the diversity of the American people."

<sup>10</sup> Office of Management and Budget, *Statistical Programs of the United States: Fiscal Years 2019-2020* 2 (Dec. 11, 2020), <https://www.whitehouse.gov/wp-content/uploads/2020/12/statistical-programs-20192020.pdf>.

<sup>11</sup> Office of Management and Budget, *Statistical Programs and Standards*, WHITEHOUSE.GOV, <https://www.whitehouse.gov/omb/information-regulatory-affairs/statistical-programs-standards/#:~:text=OMB%20Statistical%20Policy%20Directives%20identify,coordination%20of%20Federal%20official%20statistics> (last visited June 6, 2022).

<sup>12</sup> Statistical Policy Directive No. 1, 79 Fed. Reg. 71610, 71614 (Dec. 2, 2014), <https://www.govinfo.gov/content/pkg/FR-2014-12-02/pdf/2014-28326.pdf>.

<sup>13</sup> Office of Management and Budget, *Statistical Programs of the United States Government: Fiscal Year 2017* 45 (Jan. 10, 2017), [https://www.whitehouse.gov/wp-content/uploads/legacy\\_drupal\\_files/omb/assets/information\\_and\\_regulatory\\_affairs/statistical-programs-2017.pdf](https://www.whitehouse.gov/wp-content/uploads/legacy_drupal_files/omb/assets/information_and_regulatory_affairs/statistical-programs-2017.pdf).

In a recent report on statistical activities, OMB also explains that CMS “collects, analyzes, and disseminates statistical data on the Medicare and Medicaid programs and the quality of care delivered by those programs.”<sup>14</sup> Thus, Directive No. 15 should be binding on CMS and apply to data collected, analyzed, and disseminated by CMS.

## Directive No. 15 Applies to Medicaid Data Collected by States

CMS partners with states to collect demographic information on Medicaid program participants. Where state agencies collect data to submit to CMS, the standards in Directive No. 15 apply. Directive No. 15 itself never states this principle directly, but does note the given standards should be used on “administrative forms (e.g., School registration and mortgage lending applications),” which are administered by state and non-federal agencies.<sup>15</sup> OMB has stated in other publications that Directive No. 15 applies to federal statistical programs whether they are carried out by a federal agency or a state, local, or private partner by proxy.<sup>16</sup> It follows that if Directive No. 15 applies to CMS, then any entity or program carrying out a statistical activity on behalf of CMS would also be bound by it.

State Medicaid agencies appear to carry out statistical activities on behalf of CMS. On Medicaid and CHIP applications, states collect information on the race and ethnicity of Medicaid enrollees to evaluate program utilization and quality, to identify enrollees, and to ensure compliance with civil rights laws.<sup>17</sup> Although CMS does not technically require states to collect race and ethnicity information from enrollees, CMS does require states to report enrollee demographic information through a database known as the Transformed Medicaid Statistical Information system, or T-MSIS, that CMS then analyzes and disseminates.<sup>18</sup> The states’

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<sup>14</sup> *Id.*

<sup>15</sup> 62 Fed. Reg. 58782 (Oct. 30, 1997).

<sup>16</sup> Office of Management and Budget, *Statistical Programs of the United States: Fiscal Years 2019-2020* 8 (Dec. 11, 2020), <https://www.whitehouse.gov/wp-content/uploads/2020/12/statistical-programs-20192020.pdf>.

<sup>17</sup> See Heather Saunders and Priya Chidambaram, Kaiser Family Foundation, *Medicaid Administrative Data: Challenges with Race, Ethnicity, and Other Demographic Variables* (Apr. 28, 2022), <https://www.kff.org/medicaid/issue-brief/medicaid-administrative-data-challenges-with-race-ethnicity-and-other-demographic-variables/>.

<sup>18</sup> See, e.g., Centers for Medicare and Medicaid Services, *Medicaid & CHIP Scorecard*, MEDICAID.GOV, <https://www.medicaid.gov/state-overviews/scorecard/index.html> (last visited

activities, in conjunction with the activities of CMS, both appear to be the “collection, compilation, processing, analysis, or dissemination of data” that is within OMB’s definition of “statistical activity.”<sup>19</sup>

In addition to CMS’s reporting requirement, other guidance within HHS makes it clear that the minimum standards given by Directive No. 15 apply to data collected by state Medicaid programs. In 1997, HHS established its Data Inclusion Policy, which required all HHS-run and HHS-funded programs, with few exceptions, to collect data on participants’ race and ethnicity.<sup>20</sup> Wherever possible:

racial and ethnic data regarding populations served by HHS-funded programs should either be collected and reported at the providing organization level and program beneficiary level or be available at that level through use of existing data systems (e.g. matching of enrollment and claims data).<sup>21</sup>

The 1997 Data Inclusion Policy directly stated that HHS programs must use the guidance in Directive No. 15 as minimum standards for data collection on race and ethnicity.<sup>22</sup>

As an HHS-funded program, state Medicaid agencies are bound by this policy. However, in practice, CMS has not clearly stated that state Medicaid agencies must follow this policy; in

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June 6, 2022). States report eligibility and encounter data from applications, enrollment, and claims to CMS through the T-MSIS database. U.S. Dep’t of Health & Hum. Svcs., Ofc. of Inspector General, *Data on Medicaid Managed Care Payments to Providers are Incomplete and Inaccurate* (Mar. 2021), <https://oig.hhs.gov/oei/reports/OEI-02-19-00180.pdf>. T-MSIS contains person-level information on service utilization and spending. Aaron Pervin and Chris Park, Medicaid & CHIP Payment & Access Comm’n (MACPAC), *Update on Transformed Medicaid Statistical Information System (T-MSIS)* (Apr. 9, 2021), <https://www.macpac.gov/wp-content/uploads/2021/04/Update-on-Transformed-Medicaid-Statistical-Information-System-T-MSIS.pdf>.

<sup>19</sup> 79 Fed. Reg. 71610, 71614 (Dec. 2, 2014), <https://www.govinfo.gov/content/pkg/FR-2014-12-02/pdf/2014-28326.pdf>.

<sup>20</sup> Department of Health and Human Services, *Policy Statement on Inclusion of Race and Ethnicity in DHHS Data Collection Activities* (1997), <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> (last visited June 6, 2022).

<sup>21</sup> *Id.*

<sup>22</sup> *Id.* at II.D.

fact, CMS noted in 2011 that “states and the private industry are not required to follow the OMB standards.”<sup>23</sup>

It is unclear why CMS did not require states to follow the guidance in the 1997 Data Inclusion Policy. The Policy clearly states that every HHS-funded or -sponsored program, unless specifically excepted, must collect race and ethnicity data.<sup>24</sup> There are no exceptions in the policy for jointly-funded federal-state programs or programs conducted outside of HHS.<sup>25</sup> The Policy seems to contemplate its application to state Medicaid programs; its rationale explains that “the Department needs standard and reliable racial and ethnic data across the various HHS agencies and major operating components”<sup>26</sup> and that racial and ethnic data can show “the extent to which members of minority groups are beneficiaries and participants in Federally-assisted programs.”<sup>27</sup> It further acknowledges that the requirement is needed because “OMB Directive 15 provides the minimum racial and ethnic categories to be used in Federal data collections but does not require that all relevant data systems must collect data on race and ethnicity.”<sup>28</sup> The 1997 Data Inclusion Policy goes beyond Directive No. 15 in that it compels HHS-funded programs to collect race and ethnicity data from program participants, and it requires use of the standards contained in Directive No. 15.

Despite inconsistent application of the policy, each state Medicaid program now, in effect, follows the 1997 Data Inclusion Policy. A recent survey by the State Health Access Data Assistance Center (SHADAC) found that all states currently collect race and ethnicity on their Medicaid applications.<sup>29</sup> All fifty states surveyed offer at least the five race variables and two

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<sup>23</sup> Kathleen Sebelius, Dep’t of Health & Hum. Svcs., *Report to Congress: Approaches for Identifying, Collecting, and Evaluating Data on Health Care Disparities in Medicaid and Medicare* 9 (Sept. 2011), <https://www.medicaid.gov/medicaid/quality-of-care/downloads/4302b-rtc.pdf>.

<sup>24</sup> U.S. Dep’t of Health & Hum. Svcs., *Policy Statement on Inclusion of Race and Ethnicity in DHHS Data Collection Activities* at II.B (1997), <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> (last visited June 6, 2022).

<sup>25</sup> *Id.* at III.

<sup>26</sup> *Id.* at II.B.2.

<sup>27</sup> *Id.* at II.B.4.

<sup>28</sup> *Id.* at II.B.5 (emphasis added).

<sup>29</sup> State Health & Value Strategies, *Collection of Race, Ethnicity, Language (REL) Data in Medicaid Applications: A 50-State Review of the Current Landscape* 14-20 (May 2021), <https://www.shvs.org/wp-content/uploads/2021/05/SHVS-50-State-Review-EDITED.pdf>.

ethnicity variables given in Directive No. 15 as response options to the race and ethnicity question.<sup>30</sup>

Despite this development in data collection, the quality of demographic data reported by most states to CMS (coming from either applications or other claims data) falls short of the threshold for meaningful analysis. SHADAC found that most states failed to report more than 10% of enrollees' race and ethnicity information in 2019 (the most recent data available).<sup>31</sup> In comparing the race/ethnicity data reported to CMS with race/ethnicity data reported in the Census Bureau's American Community Survey (ACS), SHADAC found that the majority of CMS data differed from the data reported on the ACS by greater than 10%.<sup>32</sup> Consistency and reporting issues continue to affect the usefulness and quality of the demographic data that CMS receives from states.

## Demographic Data Collection and the Affordable Care Act

The Affordable Care Act, enacted in 2010, attempted to advance demographic data collection in Medicaid and other federal health programs. Section 4302 required federally conducted or supported health care or public health programs to collect data on race and ethnicity using the standards in Directive No. 15 as a minimum.<sup>33</sup> Section 4302 also required HHS to develop updated standards on the collection of sex, primary language, and disability status for all HHS funded and supported health care and public health programs.<sup>34</sup> As a result, HHS developed the 2011 Data Standards, which provide new guidelines for collecting information about sex, disability status, and primary language in HHS conducted and supported surveys.<sup>35</sup> The 2011

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<sup>30</sup> *Id.*

<sup>31</sup> State Health Access Data Assistance Ctr., *Race/Ethnicity Data in CMS Medicaid (T-MSIS) Analytic Files Update December 2021 – Features 2019 Data* (Jan. 2022), <https://www.shadac.org/news/raceethnicity-data-cms-medicaid-t-msis-analytic-files-updated-december-2021-%E2%80%93-features-2019>.

<sup>32</sup> *Id.*

<sup>33</sup> 42 U.S.C. § 300kk(a)(1) (2010).

<sup>34</sup> 42 U.S.C. § 300kk(a)(2) (2010).

<sup>35</sup> U.S. Dep't of Health & Hum. Svcs., *Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status* (Oct. 30, 2011), [https://aspe.hhs.gov/sites/default/files/migrated\\_legacy\\_files//43681/index.pdf](https://aspe.hhs.gov/sites/default/files/migrated_legacy_files//43681/index.pdf).

Data Standards also provided updated standards for collection of race and ethnicity information, further disaggregating the race and ethnicity variables used by Directive No. 15.<sup>36</sup>

Compared to the charge given in the statute to develop new demographic data collection standards for “any federally conducted or supported health care or public health program,”<sup>37</sup> the 2011 Data Standards are fairly limited in application. The language of the 2011 Data Standards clearly states that the standards apply only to population-based surveys, not all HHS programs.<sup>38</sup> Therefore, the 2011 Data Standards do not apply to data reported in Medicaid and CHIP.

CMS has not taken definitive public action to adopt the updated 2011 Data Standards as official guidelines for collecting demographic data in Medicaid programs.<sup>39</sup> However, even without formally adopting the 2011 Data Standards, CMS does use the race and ethnicity variables in the 2011 Data Standards as options to report demographic information through

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<sup>36</sup> *Id.* at 2-4.

<sup>37</sup> 42 U.S.C. § 300kk(a)(1) (2010).

<sup>38</sup> U.S. Dep’t of Health & Hum. Svcs., *Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status* 8 (Oct. 30, 2011), [https://aspe.hhs.gov/sites/default/files/migrated\\_legacy\\_files//43681/index.pdf](https://aspe.hhs.gov/sites/default/files/migrated_legacy_files//43681/index.pdf). “This policy applies to population-based health surveys conducted or sponsored by HHS, in which respondents either self-report information or a knowledgeable proxy provides information about the person or responds for all persons in a household.” CMS may have chosen not to formally adopt the 2011 Data Standards because of the limitation in subsection (h) of Section 4302 of the Affordable Care Act. Subsection (h) restricts demographic data collection under the new requirement “unless funds are directly appropriated for such purpose in an appropriations Act.” 42 U.S.C. § 300kk(h) (2010). Since no funds have been appropriated beyond those initially provided, the statute’s broad demographic data collection requirements remain in limbo. These circumstances may seem to inhibit data collection; however, as reviewed above, both Directive No. 15 and the 1997 Data Inclusion Policy gave authority for demographic data collection well in advance of the ACA, and still appear to be operative.

<sup>39</sup> Ctrs. for Medicare & Medicaid Svcs., *Inventory of Resources for Standardized Demographic and Language Data Collection* (Mar. 2022), <https://www.cms.gov/about-cms/agency-information/omh/downloads/data-collection-resources.pdf> (last visited July 19, 2022). This resource document states that the minimum standards in Directive No. 15 apply to data collection in Medicaid. It mentions the 2011 Data Standards but stops short of stating that the race and ethnicity language in the 2011 Data Standards must be used by Medicaid programs.

the T-MSIS system.<sup>40</sup> Therefore, states must align the demographic information they have collected with the variables from the 2011 Data Standards in order to report the race and ethnicity of enrollees to CMS through T-MSIS.

## **CMS Can – And Should – Directly Require States to Report Race and Ethnicity Data on Medicaid Enrollees**

CMS currently has authority to require states to collect and report information on enrollees' race and ethnicity. Whether under the charge of Directive No. 15, civil rights statutes such as Title VI of the Civil Rights Act of 1964 or Section 1557 of the ACA, or general program administration authority, CMS has been directed to monitor program performance, understand the needs of program participants, and comply with civil rights laws.

With its Framework for Health Equity, CMS committed to broaden demographic data collection within its programs to identify and monitor health disparities.<sup>41</sup> CMS now has an opportunity to advance that objective by clarifying the standards that apply to Medicaid and CHIP programs across the country. We offer the following suggestions of administrative actions for CMS to take under its current statutory and regulatory authority.

First, CMS should issue new guidance that sets out standards and expectations for states to report demographic data. Uniform standards promote better quality data and facilitate a better understanding of disparities from state to state. Second, CMS must provide adequate technical support and resources to states seeking to improve data quality. CMS can highlight research-informed data collection practices and remind states that an enhanced FMAP is available to update data systems. Third, CMS must also update its own databases and systems, such as T-MSIS, to facilitate easier data reporting from states. Finally, CMS must ensure that reporting on demographic data and health disparities can be accessed by states, researchers, and the public. As health inequities come to light, the public and particularly underserved communities play a vital role in holding health systems accountable to serve the public equitably.

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<sup>40</sup> See *CMS Technical Instructions: Reporting Race and Ethnicity in the T-MSIS Eligible File*, MEDICAID.GOV, <https://www.medicaid.gov/medicaid/data-and-systems/macbis/tmsis/tmsis-blog/109701> (last visited Aug. 3, 2022).

<sup>41</sup> Ctrs. for Medicare & Medicaid Svcs., *CMS Framework for Health Equity 2022-2032* 12 (2022), <https://www.cms.gov/files/document/cms-framework-health-equity.pdf>.

## Issue New Guidance Clarifying States' Obligations to Report Demographic Data

CMS should issue guidance that formally sets out demographic data collection requirements for state Medicaid programs. Although all states currently collect race and ethnicity information from enrollees on their applications, data reported from states varies in completeness and quality. These two actions – collecting and reporting – go hand in hand. Clear and unambiguous guidance would underscore the importance of demographic data collection to data quality, help states standardize their practices, and improve states' ability to advance equity in their programs.

CMS's guidance should first and foremost standardize the race and ethnicity variables that states use to collect demographic data on the Medicaid and CHIP application and report that data to CMS. Requiring states to use standardized race and ethnicity variables ensures that states and CMS can compare data efficiently and effectively from state to state and program to program. Because most states engage with private entities to run managed care programs, CMS should explicitly state that the guidance applies to all aspects of state-run Medicaid programs, whether demographic data is collected by the state Medicaid agency or a private partner.

We recommend that CMS start by adopting the 2011 Data Standards as the standard set of race and ethnicity variables that states use when collecting information about race and ethnicity. Even though all states at minimum appear to offer the five race variables and two ethnicity variables required by Directive No. 15, these standards no longer provide sufficient granularity to understand our diverse population. The 2011 Data Standards offer fourteen race options and five ethnicity options, which expand on and “roll up to” the standards provided by Directive No. 15. OMB contemplates and encourages this “roll up” approach in Directive No. 15, which specifically states that the standards are intended as a minimum; statistical programs are encouraged to add expanded race and ethnicity variables as long as they “roll up” to the minimum categories in the Directive.<sup>42</sup>

In creating its guidance, CMS should recommend data collection and reporting at multiple points of enrollee contact. For example, states should collect information on enrollees' race and ethnicity on the Medicaid application, during enrollment in a managed care plan, and at additional interactions: provider visits, redeterminations, plan contacts, or hospital admissions.

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<sup>42</sup> 62 Fed. Reg. 58783 (Oct. 30, 1997). “The categories should set forth a minimum standard; additional categories should be permitted provided they can be aggregated to the standard categories. *Id.*”

Collecting self-reported information on race and ethnicity at several instances improves the usefulness and completeness of data because it allows the information received from the enrollee to be cross-checked for accuracy or assessed for missing fields. CMS should clarify at what points demographic data collection is mandatory, but ensure that such information must be voluntarily self-reported from enrollees.

CMS's guidance should include a timeline for adopting the standards and a procedure for regular review of the demographic data collection policy. Populations shift, community input may change, and language around identity is constantly in flux. CMS may also encounter changes in federal policy with regard to data collection; for instance, OMB has begun a two-year review of the standards in Directive No. 15, which may result in changes to the minimum race and ethnicity variables.<sup>43</sup> CMS should proactively engage with stakeholders – including community organizations, enrollees, providers, and advocates – during each review by conducting outreach and inviting feedback from those less likely to participate in the public notice and comment process. In convening diverse stakeholders and communities to provide input, CMS will improve the likelihood of participation in data collection efforts as well as increase the utility of the data collected.<sup>44</sup>

Finally, any guidance issued must include clear language on privacy protections afforded to demographic information shared by enrollees and what enrollees must be informed about those privacy protections. Enrollees may be more likely to voluntarily report information on race and ethnicity when they understand how the information will be used or shared.<sup>45</sup> States

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<sup>43</sup> Karin Orvis, *Reviewing and Revising Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity*, THE WHITE HOUSE: BRIEFING ROOM BLOG (Jun. 15, 2022), <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/>.

<sup>44</sup> See, e.g., Victor Rubin et al., PolicyLink, *Counting a Diverse Nation: Disaggregating Data on Race and Ethnicity to Advance a Culture of Health* 24-26 (2018), [https://www.policylink.org/sites/default/files/Counting\\_a\\_Diverse\\_Nation\\_08\\_15\\_18.pdf](https://www.policylink.org/sites/default/files/Counting_a_Diverse_Nation_08_15_18.pdf); Stella S. Yi et al., *The Mutually Reinforcing Cycle of Poor Data Quality and Racialized Stereotypes That Shapes Asian American Health*, HEALTH AFF. (Feb. 2022), <https://www.healthaffairs.org/doi/10.1377/hlthaff.2021.01417>; Karen Wang et al., *Centering Equity in the Design and Use of Health Information Systems: Partnering with Communities on Race, Ethnicity, and Language Data*, HEALTH AFF. (May 19, 2021), <https://www.healthaffairs.org/doi/10.1377/forefront.20210514.126700/full/>.

<sup>45</sup> See Ruben D. Vega Perez et al., *Improving Patient Race and Ethnicity Data Capture to Address Health Disparities: A Case Study from a Large Urban Health System*, 14 CUREUS 1,

must clearly communicate the expectation of confidentiality and the extent to which privacy laws apply to demographic information shared by participants. States must also be clear on the role that they play in keeping enrollee information confidential. CMS should identify and adopt data analysis methods that prevent smaller populations from being personally identified.<sup>46</sup>

## Provide Updated Technical Assistance and Increased FMAP to States

State agencies and partners will likely need technical and administrative support to implement changes in demographic data practices and policies. CMS should provide a composite of resources to assist states, providers, and plans in adapting.<sup>47</sup> CMS should create training modules for front-line staff at Medicaid agencies, managed care plans, and call centers; provide sample language for state Medicaid applications and forms; offer technical assistance and support for states who must change their forms, computer systems, and databases; and implement other research-tested means to improve data accuracy and facilitate staff-enrollee interactions.

Two recent studies provide an example of the types of resources CMS could provide. In a 2022 study targeted at providers, a New York City health system tested methods to improve demographic data collection practices and reduce the occurrence of missing and inaccurate data.<sup>48</sup> The study identified several interventions that ultimately reduced missing data by 76%

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(2022) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8815799/>; Elizabeth Lunkenen and Emily Zylla, *Exploring Strategies to Fill Gaps in Medicaid Race, Ethnicity, and Language Data*, SHADAC (2020), <https://www.shvs.org/exploring-strategies-to-fill-gaps-in-medicaid-race-ethnicity-and-language-data/>.

<sup>46</sup> For suggested principles that balance privacy with disaggregation, see Victor Rubin et al., PolicyLink, *Counting a Diverse Nation: Disaggregating Data on Race and Ethnicity to Advance a Culture of Health* (2018), 35-36  
[https://www.policylink.org/sites/default/files/Counting\\_a\\_Diverse\\_Nation\\_08\\_15\\_18.pdf](https://www.policylink.org/sites/default/files/Counting_a_Diverse_Nation_08_15_18.pdf).

<sup>47</sup> The one that is available offers examples of resources but does not itself provide recommendations. See Ctrs. for Medicare & Medicaid Svcs, *Inventory of Resources for Standardized Demographic and Language Data Collection* (Mar. 2022), <https://www.cms.gov/about-cms/agency-information/omh/downloads/data-collection-resources.pdf>.

<sup>48</sup> Ruben D. Vega Perez et al., *Improving Patient Race and Ethnicity Data Capture to Address Health Disparities: A Case Study from a Large Urban Health System*, 14 CUREUS 1, (2022) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8815799/>.

over five years, including: developing training materials for frontline staff; addressing patient concerns; soliciting feedback from patients; modifying technology and infrastructure to support new data collection; identifying lead data collection personnel; and periodically reassessing the data collection program.<sup>49</sup> Overall, the study emphasized the need for buy-in from the patient population, clinicians, leadership, and frontline staff for the data collection effort to succeed.<sup>50</sup>

An additional study explored strategies for a state to improve race and ethnicity responses specifically on the Medicaid and CHIP application.<sup>51</sup> The study identified several strategies that improved the demographic question response rate: messaging the importance of data collection to enrollees; asking for a response, even if the response is “decline to answer”; training assistors and navigators on how to ask race/ethnicity questions; and incorporating feedback from program evaluations. These studies provide a blueprint for CMS to build a data collection toolkit and provide technical assistance to states as they seek to improve their practices.

CMS should clarify that an increased FMAP rate is available for states who need to implement changes to technical databases; conduct trainings, reviews, and evaluations; hire consultants or implementation staff, such as statisticians; and update systems. As with the implementation of the MMIS and T-MSIS systems, and the implementation of new information systems after health care reform, an FMAP of 90% is available to provide administrative technical support in upgrading information systems.<sup>52</sup>

## Update T-MSIS and Internal CMS Data Repositories

Along with any effort to promote readiness among state Medicaid agencies and partners, CMS must also review its own systems, forms, and databases to ensure that it is ready to receive input from states. CMS must continue to make improvements to the T-MSIS system to make

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<sup>49</sup> *Id.*

<sup>50</sup> *Id.*

<sup>51</sup> Colin Planalp, State Health Access Data Assistance Center (SHADAC), *New York State of Health Pilot Yields Increased Race and Ethnicity Question Response Rates*, STATE HEALTH & VALUE STRATEGIES (Sept. 9, 2021), <https://www.shvs.org/new-york-state-of-health-pilot-yields-increased-race-and-ethnicity-question-response-rates/>.

<sup>52</sup> 42 U.S.C. 1396b(a)(3)(A)(i); 42 C.F.R. 433; Kaiser Comm’n on Medicaid and the Uninsured, Kaiser Family Foundation, *Medicaid Financing: An Overview of the Federal Medicaid Matching Rate (FMAP)* 9 (Sept. 2012), <https://www.kff.org/wp-content/uploads/2013/01/8352.pdf>.

sure states can report data accurately and that the data can be shared in a timely manner. For a broader discussion of T-MSIS quality issues, see National Health Law Program, *Addressing Health Equity in Medicaid Managed Care*.<sup>53</sup>

## Promote Transparency and Accessibility of Data and Analysis

CMS must also be clear and transparent in how demographic data collected from Medicaid enrollees is used and shared. Non-governmental organizations and nonprofits promote accountability in use of demographic data by putting data about health disparities in the hands of communities who are most disadvantaged by those disparities. Making that data accessible enables and empowers these underserved communities to meaningfully participate in and lead in shaping solutions to achieve equity. Currently, the information contained within T-MSIS costs thousands of dollars to obtain, which is prohibitively expensive for university-affiliated researchers, let alone smaller community-led organizations. This barrier prevents the flow of information to communities that allows them to meaningfully participate in policy solutions as well as the ability for communities to have control over information that originates with them.

Data collected through T-MSIS, including demographic information, must be shared with both researchers and community-led organizations in a timely manner. In addition to the expense, untimely information creates a barrier to responsiveness and makes it difficult to identify long-term or short-term trends. There has historically been several years' delay before T-MSIS data files become available for researchers.<sup>54</sup> In the meantime, advocates and stakeholders are limited to pre-sorted information that CMS makes available.

## Conclusion

HHS's 1997 Data Inclusion Policy requires CMS to collect the race and ethnicity of participants in the Medicaid and CHIP programs using at least the standards given by Directive No. 15. These policies, along with statutory authority in Title VI of the Civil Rights Act and general program administrative authority, allow CMS to engage in comprehensive demographic data collection without further rulemaking or Congressional action.

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<sup>53</sup> David Machledt, Nat'l Health Law Program, *Addressing Health Equity in Medicaid Managed Care* (May 2021), <https://healthlaw.org/resource/addressing-health-equity-in-medicaid-managed-care/>.

<sup>54</sup> *Id.* at 5.

CMS should not wait to begin using that authority. We recommend that CMS issue clear guidance requiring states to collect demographic information of enrollees at the application and several points of contact, using the race and ethnicity variables found in the 2011 Data Standards. To fulfill its obligation to remedy serious and persistent health disparities in Medicaid and CHIP, CMS must ensure consistency of data collection, provide technical assistance and resources to improve the comprehensiveness of data collection, and allow the public to see the resulting data. CMS should continue to revise its demographic data collection policy with stakeholder feedback and provide support to states as they seek to improve their own data collection and reporting processes.