Federal Action Is Needed to Improve Race and Ethnicity Data in Health Programs

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Executive Summary

The COVID-19 pandemic laid bare the inequities in health and health care in the U.S., but the lack of adequate data on race and ethnicity prevented an effective response. Urgent action is necessary to improve race and ethnicity data in federal health programs that serve millions of Americans. Such data are pivotal to providing access to care, mounting effective and timely responses to health crises, eliminating racial and ethnic disparities, and advancing health equity. This paper presents findings and recommendations based on an environmental scan of selected health programs and over 20 interviews with key informants representing federal, state, and local health agencies; commercial insurance plans; public and private health systems; and health information technology experts. Examination of federal and state health care and public health programs reveals an absence of complete, standardized, self-identified race and ethnicity data sufficient to monitor equity. Key actions the federal government can take now to improve race and ethnicity data—and, in so doing, advance health equity—are highlighted below.

Recommendations for Improving Federal Race and Ethnicity Data

To improve federal race and ethnicity data, the government must make it a priority. Making complete and accurate race and ethnicity data a priority increases the likelihood that resources will be allocated to support the effort and that progress will be made. The federal government has multiple levers with which it can effect change. These include but are not limited to rulemaking, guidance, the bully pulpit, technical assistance, and outreach and education. The government also needs to provide stakeholders with a clear vision and guidance on how to achieve that vision.

1. The federal government should review and update the Office of Management and Budget (OMB) 1997 Statistical Policy Directive on Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity to more accurately reflect the demographics of the population of the United States and provide flexibility to states and local governments to capture information reflecting the populations specific to their communities.

2. The Centers for Medicare & Medicaid Services (CMS) should include race and ethnicity on the Medicare Part C & D application.

3. The Interagency Working Group on Equitable Data (Data Working Group) should review existing data systems and work through OMB to standardize the collection and reporting of racial, ethnic, and other demographic data across the federal government (e.g., Department of Agriculture (USDA), CMS, and Health Resources and Services Administration (HRSA) reporting requirements) while providing states, local governments, and grantees the flexibility to collect data on other population groups residing in their area.

(4) The Department of Health and Human Services (HHS) should review and edit provider data systems to collect information on provider demographics, and work with the Bureau of Labor Statistics at the Department of Labor to help ensure that the population caring for communities reflects the demographics of those communities.

(5) OMB should require all federal program reports to include data stratified by race, ethnicity, and other demographics where feasible.

(6) HHS should require state and local health departments, Medicaid programs, public health, and human service programs to conduct an audit of their race and ethnicity data to identify information gaps and barriers to completion.

(7) HHS and other departments should support states through technical assistance and financial assistance to improve data systems and interoperability, as well as improved analytic and reporting capacity.

(8) HHS should develop educational resources on the importance of asking an individual about their race and ethnicity, and resources on why it is important to answer the questions and how the information will be used. In addition, HHS should work with myriad stakeholder groups (e.g., providers, consumer and community-based organization, public health, etc.) to disseminate the information.

(9) Include community voices in the development and dissemination of materials explaining why the information is collected, how it will be used, and why it is important to collect.

(10) Congress should review and amend as necessary the Health Information Portability and Accountability Act (HIPAA), the Family Educational Rights and Privacy Act (FERPA), the Patient Protection and Affordable Care Act (ACA), and other data laws to encourage the collection and sharing of information across health, human and social services, including the justice system.

(11) Improving privacy protections of data captured through health apps, such as increasing the Federal Trade Commission's (FTC) authorization since they manage the health apps.

In sum, the federal government can invest resources in data system changes and education and technical assistance for expanding collection and use of race and ethnicity data. It can also increase incentives to collect and assess these data and, in cases, require that federal program participants do so. Finally, by reviewing existing regulation to assess where current policy may restrain (or create the appearance of prohibiting) collection of race and ethnicity data, the federal government can empower stakeholders to pursue these necessary efforts.

The pandemic's toll has galvanized the nation to act. This moment of collective momentum for change provides a unique opportunity that we have not had before, and we may not see again. Federal action to strengthen the collection and quality of race and ethnicity data in health programs is foundational to improving the quality of care and achieving equitable health outcomes.

The COVID-19 pandemic laid bare the inequities in health and health care in the U.S., but the lack of adequate data on race and ethnicity prevented an effective response. Urgent action is necessary to improve race and ethnicity data in federal health programs that serve millions of Americans. Such data are pivotal to providing access to care, mounting effective and timely responses to health crises, eliminating racial and ethnic disparities, and advancing health equity.

This paper highlights key actions the federal government can take now to improve race and ethnicity data and, in so doing, advance health equity. The findings and recommendations are based on an environmental scan of selected health coverage programs, federal delivery systems and public health data and over 20 interviews with key informants representing federal, state, and local health agencies; commercial insurance plans; public and private health systems; and health information technology experts. Achieving health equity requires a holistic approach, addressing the health and social needs of individuals and communities and also racial inequities. This paper focuses on race and ethnicity data and complements other efforts underway addressing data needs related to social determinants of health.

Why is now the time for the federal government to take action to modernize the data infrastructure in health programs?

The consequences of COVID-19 cannot be ignored. The pandemic provides tragic evidence that the racial and ethnic gaps in health care access, quality, and outcomes documented for more than a century persist. Several months into the pandemic, we did not know who was getting tested or, when vaccines became available, who was getting vaccinated despite knowing about the disproportionate impact on Black, Indigenous and other communities of color. These disparities in COVID-19 infections, hospitalizations, morbidity and mortality, and vaccinations magnify the urgency to have data that can inform our response to inequities stemming from differences in the social determinants of health, such as employment, food, and housing. The magnitude of the evidence documenting ongoing racial and ethnic disparities, when combined with societal resolve to address structural racism, creates an opportunity to eliminate disparities and be better prepared to respond to future crises.

Missing data means missed opportunities to eliminate health and health care disparities. When race and ethnicity data are incomplete or inconsistently collected in health programs, we limit our ability to recognize, monitor, and tackle health disparities and provide quality health care. Lack of race and ethnicity data in health programs impedes progress on improving the health of populations across the U.S. and are particularly severe for small population groups, such as American Indians and Alaska Natives. Multiple reasons are cited for the gaps in race and ethnicity data, including: a lack of up-to-date data collection standards, old data systems, concern about asking individuals for the information and misperceptions about what is allowable legally, concern about how the information may be used, and, in some cases, failure to request the information. However, missing data obscures our ability to see problems that can be addressed and creates the potential for unintended consequences that perpetuate or increase disparities.

The pandemic's toll has refocused attention on racial equity and galvanized the nation to act. As policymakers develop strategies to address the underlying structural factors that led to the disparities exposed and exacerbated by the pandemic, we have an imperative to build on the substantial research base to make progress. The 1985 Heckler Report, the first national report to address health disparities, along with subsequent work during the 1990s and 2000s laid the groundwork for today's efforts to advance health equity. This moment of collective recognition of racial inequities and momentum for change provides a unique opportunity that we have not had before and may not see again. The Biden Administration has signaled this as well, with public statements like its *Executive Order On Advancing Racial Equity and Support for Underserved Communities Through the Federal Government*. We have an opportunity to take action at the federal level to address these barriers and to strengthen the collection and quality of race and ethnicity data in health programs. This work is foundational to improve quality of care and the nation's health.

What is the state of race and ethnicity data in health programs today?

Federal standards and processes leave critical data gaps. Examination of federal and state health care and public health programs reveals an absence of complete, standardized, self-identified race and ethnicity data sufficient to monitor equity. Although widely used, race and ethnicity standards released by the OMB in 1997 do not adequately reflect the demographic diversity of the U.S. population today and have not kept pace with how people self-identify. HHS data standards published by the Assistant Secretary for Planning and Evaluation (ASPE) in 2011 more accurately reflect the diversity of the population. The Affordable Care Act (ACA) requires these data collection standards in national population health surveys for the examination of health and health care disparities, but their use in federal health programs varies. Table 1 presents a comparison of these two standards.

Table 1: Comparison of OMB 1997 and HHS 2011 Race and Ethnicity Collection Standards

	OMB 1997	HHS 2011
Race*	White	White
	Black or African American	Black or African American
	American Indian or Alaska Native	American Indian or Alaska Native
	Asian	Asian Indian Chinese Filipino Japanese Korean Vietnamese Other Asian
	Native Hawaiian or Other Pacific Islander	Native Hawaiian Guamanian or Chamorro Samoan Other Pacific Islander
Ethnicity*	Hispanic or Latino	No, not of Hispanic, Latino/a, or Spanish origin
	Not Hispanic or Latino	Yes, Mexican, Mexican American, Chicano/a Yes, Puerto Rican Yes, Cuban Yes, Another Hispanic, Latino/a or Spanish origin

* OMB 1997 and HHS 2011 permit the reporting of more than one race; HHS 2011 also permits people to select one or more ethnicity.

While the HHS 2011 standards expanded the number of categories, they do not necessarily provide the granularity needed to reflect individuals' self-identification and to understand differences in service use and outcomes. This is particularly true for certain identities, including Asians, Native Hawaiians and Other Pacific Islanders, American Indians and Alaska Natives, and people coming from Middle Eastern or North African countries. Moreover, the HHS standards lack the ability to reflect the diversity of many local areas across the country. More recent efforts like the Office of the National Coordinator for Health Information Technology (ONC)'s 2015 Edition final rule incorporate an expanded code set for race and ethnicity that encompasses over 900 ways of representing racial and ethnicity self-identification.

The completeness of the data, reflecting the percentage of the population with a recorded race and ethnicity, varies widely across programs. Imputation methods and probabilistic modeling are sometimes used to fill these gaps. Some stakeholders observed that while these methods can be useful at a population level, they should not be used at the individual level because they can lead to faulty conclusions. Imputation methods also are not as accurate for smaller population groups, including American Indian and Alaska Natives and because they do not identify Native Hawaiians and Other Pacific Islanders (NHOPI). Further, the accuracy of current data is unknown for many programs even when data is relatively complete. Efforts to assess the validity of race and ethnicity data in federal administrative sources have not been consistently undertaken.

Self-identification, considered the gold standard for race and ethnicity data collection, is recognized by both the OMB 1997 and HHS 2011 standards as the preferred means of data collection; however, program administration processes do not require or encourage it. Stakeholders pointed to a number of real and perceived barriers to collecting the data, including lack of incentives or requirements, uncertainty over best practices, and privacy concerns. Self-reported data may also be collected as part of health care delivery, health assessment tools, and electronic health records, but practices vary widely. Still, the validity of this information is uncertain and there are not clear processes for sharing data across settings or programs and using data to improve administrative records.

When health program data is available by race and ethnicity, these data can convey important information to providers, policymakers, and the public. The ability to analyze health program data is essential to identifying disparities and population groups at-risk, enhancing access to care and improving the quality of care. Some race and ethnicity data are available to the public or researchers as public-use file (PUFs) or researcher identifiable file (RIF), while others are more restricted. Accessing these data resources can also be expensive and technologically resource intensive.

The completeness and quality of federal race and ethnicity data varies widely across health programs. The federal government plays an essential role in many health programs, including as an important purchaser of health care services through Medicare and, in partnership with the states, through Medicaid, as a provider of care through federal delivery systems, and in administering several public health databases. As a result, the federal role in data collection is essential to improving collection, quality and availability of race and ethnicity data in health programs. Table 2 presents a high-level summary of quality and completeness of race and ethnicity data collected at enrollment for selected health programs.

Race and ethnicity data are comparatively complete for Medicare beneficiaries, although there are well documented limitations related to changing data sources and standards over time. Before 1989, Medicare's Enrollment Database (EDB) relied on data collected by the Social Security Administration (SSA) derived from the Social Security application. Prior to 1980, SSA collected voluntarily provided race data for the categories White, Black, and Other, with missing data classified as unknown. In 1980, standards were expanded to include White (non-Hispanic), Black (non-Hispanic), Hispanic, Asian/Asian American/Pacific Islander, and American Indian or Alaska Native. When SSA switched to enrollment at birth, the race and ethnicity information on birth certificates was not recorded in SSA enrollment records, resulting in missing data for beneficiaries born after 1989. Despite subsequent steps by CMS to improve the accuracy of the race and ethnicity data, challenges remain for some population groups.

Medicaid race and ethnicity data is available through the Transformed Medicaid Statistical Information System (T-MSIS). Although all states collect self-reported race and ethnicity during the Medicaid application process, the granularity and completeness of the data is highly variable due to differences in state data collection and reporting processes. HHS provides guidance but does not require states to use the HHS 2011 standards and questions regarding race and ethnicity must be identified as optional. State data collection efforts are further complicated by lack of alignment of standards across federal health and social services programs, such as Medicaid and Supplemental Nutrition Assistance Program (SNAP). As with Medicaid, the quality and completeness of race and ethnicity data in Marketplace insurance plans varies considerably state to state. State-based and federally-facilitated marketplaces (SBMs and FFMs) use different standards for collection and reporting and rates of missing data vary widely. Race and ethnicity data on the commercially insured are mostly incomplete.

Federal delivery systems, including the Veterans Health Administration (VHA), Indian Health Service (IHS), and Federally Qualified Health Centers (FQHCs) have high rates of self-identified data, but the data's utility is limited. For example, FQHCs collect robust data from patients served, but data reporting is aggregated at the center level and thereby limits opportunities for understanding differences in use and outcomes across race and ethnicity groups.

A range of federal public health data is collected through vital statistics, surveillance and tracking. Data collection methods vary across these efforts, as does the quality of the race and ethnicity data. The federal Immunization Information System (IIS) draws on systems administered by states, territories, and local governments. The federal system calls for use of the OMB 1997 standards, but implementation is uneven with variability in data quality and completeness. For example, the race and ethnicity data collected for COVID-19 is improving but is not consistently collected by states and reporting standards vary. As of August 2021, race and ethnicity data were available for only 58% of people who have received one dose of the vaccine.

Processes for data sharing are not standardized across federal programs.

Race and ethnicity data that are collected by public programs and health care entities is not conveyed across the system in a standardized way. Within HHS, data sharing and interoperability across programs and agencies is limited. Further, race and ethnicity data does not easily flow between HHS and other federal programs outside of HHS, such as SNAP, education, and housing. As a result, some stakeholders noted that race and ethnicity data that is collected can be siloed within programs and not easily accessed to fill in missing data across programs or to inform decisionmaking.

Even when data are available, there is limited insight into equity.

High quality race and ethnicity data are fundamental to the ability of the federal government to understand the causes of health disparities, design effective responses, and track and evaluate progress in reducing disparities. In public programs, collection of race and ethnicity happens at enrollment but is much less standardized at other points in care delivery. Medicare Advantage stands out as an area where it is possible to assess equity in clinical quality and care experiences (although some portion is based on imputed data). The Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys capture self-reported race and ethnicity data that has been used to examine equity in care experiences in Medicare fee-for-service and Medicare Advantage. The CAHPS race and ethnicity data are used in stratified Medicare Advantage performance reporting by the CMS Office of Minority Health. This is not true for Medicaid or Marketplace, where federal quality reporting does not support equity analyses.

As technology advances, federal patient privacy protections may not be adequate.

The proliferation of health apps can support the ability of patients to self-identify and provide their data in private without the need for a face-to-face interaction. However, stakeholders noted that while these systems have the potential to empower patients, it is essential that patients understand how their data will be used and be empowered to share, not share or unshare data. Technology start-ups developing new products are not necessarily knowledgeable about equity issues and have competing market pressures to collect and use data. Health systems can be partners in these education efforts, but the federal government also has a role to ensure that regulatory safeguards are sufficient to protect patient privacy in this rapidly evolving market.

Table 2: Race and Ethnicity Data Collected at Enrollment in Selected Health Programs

SETTING	DATA COLLECTION STANDARD	COMPLETENESS	SELF-REPORTED?	DATA AVAILABLE FOR RESEARCH?
Medicare	Standards have changed over time	●	✔ [a]	✔
Medicaid	HHS 2011 [b]	◗	✔	✔
Federally-Facilitated and State-Based Marketplaces (FFMs; SBMs)	FFMs HHS 2011; SBMs vary	◗	◗	✔
Commercial Insurance	Unknown	○	Unknown	✗
Veterans Health Administration	OMB 1997	●	◗	✗
Indian Health Service	Blood Quantum & Tribal Affiliation	◗ [c]	Unknown	✔
Federally Qualified Health Centers	OMB 1997	●	✔ [d]	✔ [d]
Birth Records	HHS 2011	●	✔ [e]	✔
COVID-19 Vaccinations	OMB 1997	◗	Unknown	✔
Pregnancy Risk Assessment Monitoring System	OMB 1997	◗	✔ [f]	✔

LEGEND: ○ Less complete   ◗ Varies (by state, collection method, etc.)   ● More complete   ✔ Yes   ✗ No

NOTES:

a Data are obtained by SSA from the parents at birth, but data are not available for most beneficiaries born after 1989 due to SSA procedure changes.
Also includes imputation to improve reporting for Asian and/or Pacific Islanders & Hispanic beneficiaries.

b Data categories roll up to OMB 1997 standards.

c Limited to data from individuals receiving care at IHS providers; 78% American Indians and Alaska Natives live outside tribal statistical areas.

d Data aggregated at center level.

e Based on mother & father self-report.

f Extracted from birth certificate.

Recommendations for Improving Federal Race and Ethnicity Data

To improve federal race and ethnicity data, the government must make it a priority. There are several recent examples of how the government has prioritized health data such as the switch from International Classification of Diseases (ICD) 9 to ICD-10 in 2015, the transition from the Medicaid Statistical Information System (MSIS) to the Transformed Medicaid Statistical Information System (T-MSIS) in 2017 and the replacement of the Sustainable Growth Rate (SGR) law with the Quality Payment Program (QPP) in 2017. These efforts required significant resources, education, and support. Improving the completeness, quality, and utilization of racial and ethnic data in federal and state programs will require the same effort. Making it a priority increases the likelihood that attention will be paid, resources will be allocated to support the effort, and progress will be made. The federal government has multiple levers with which it can effect change. These include but are not limited to rulemaking, guidance, the bully pulpit, technical assistance, and outreach and education. The current administration has begun to make progress in that direction, as exemplified by actions like the _Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government,_ which includes provisions to establish an "Equitable Data Working Group." Without sufficient data on race and ethnicity, these efforts will fail to live up to their potential.

In addition to making the collection of accurate racial and ethnic data a priority, the government needs to provide stakeholders with a clear vision and guidance on how to achieve that vision. Many of the stakeholders we spoke with believe that in the absence of a clear vision and guidance, we will continue to be limited in our ability to identify and understand racial and ethnic health disparities. The following recommendations are grouped into four categories: Changes in Data Standards and Systems; Incentives and Requirements; Education and Technical Assistance; and Regulation.

Changes in Data Standards and Systems

Data systems and standards refer to the tools and procedures used to collect, store, and share race and ethnicity data. Stakeholders identified key ways in which the categories used to describe racial and ethnic self-identification could be updated, and in which the federal government could standardize and modernize how it collects and shares such data.

1. **The federal government should review and update the OMB 1997 Statistical Policy Directive on Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity to more accurately reflect the demographics of the population of the United States and provide flexibility to states and local governments to capture information reflecting the populations specific to their communities.**

   In 2016, OMB convened federal agencies and sought public comment on proposed changes, such as including Hispanic as part of the race options and adding an additional race category for Middle Eastern and North African, but never finalized the recommended changes.

2. **CMS should include race and ethnicity on the Medicare Part C & D application.**

   Currently, CMS obtains race and ethnicity on Medicare beneficiaries at the time of enrollment from the Social Security Administration, who obtains the data from an individual's birth certificate. For most beneficiaries, those categories predate the OMB 1997 Directive. Additionally, beginning in 1990, SSA implemented a new process for issuing social security

numbers at birth. In doing so, they opted not to include race and ethnicity among the information requested. As a result, SSA is not able to provide race and ethnicity data for beneficiaries born after 1990. The proportion of Medicare beneficiaries enrolled in Medicare Advantage has grown significantly in the past decade to include nearly 40 percent of all beneficiaries, and more than 75 percent of Medicare beneficiaries are enrolled in a Part D plan. Collecting the data at enrollment in Part C and D will help fill the void and allow for data to be collected reflecting the current data standards. Additional recommendations for improving racial and ethnic data in Medicare can be found in a report CMS submitted to Congress in 2017.

③ **The Interagency Working Group on Equitable Data (Data Working Group) should review existing data systems and work through OMB to standardize the collection and reporting of racial, ethnic, and other demographic data across the federal government (e.g., USDA, CMS, and HRSA reporting requirements) while providing states, local governments, and grantees the flexibility to collect data on other population groups residing in their area.**

The federal government should review all data systems to ensure that where appropriate, race and ethnicity data are collected, and that the programs and systems allow for more granular data such as the HHS race and ethnicity data categories. Some stakeholders expressed frustration at the inconsistency across federal programs in the way they require race and ethnicity data to be submitted, and at the limited flexibility for more granular categories. For example, the Uniform Data System includes data from community health centers and asks respondents to report race data for their patient population using one of eight categories: 1) Asian, 2) Native Hawaiian, 3) Other Pacific Islander, 4) Black/African American, 5) American Indian/Alaska Native, 6) White, 7) More than One Race, or 8) Unreported/Refused to report race. Meanwhile, the Transformed Medicaid Statistical Information System (T-MSIS) includes more detailed categories for Native Hawaiian and Other Pacific Islander consistent with the HHS standards, and the Women and Infants (WIC) includes Native Hawaiian and Pacific Islander as one racial population, consistent with the OMB 1997 Directive.

④ **HHS should review and edit provider data systems to collect information on provider demographics, and work with the Bureau of Labor Statistics at the Department of Labor to help ensure that the population caring for communities reflects the demographics of those communities.**

Much of the data related to disparities focuses on the patient or the institution from which they receive care, with considerably less attention paid to the individuals providing care. Two of the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (The National CLAS Standards), developed by HHS, emphasize the importance of recruiting and developing a diverse workforce and collecting demographic data to monitor disparities and support service delivery suggestions. Having a better understanding of who is providing care at all levels, from doctors and nurses to nursing home, home health and community health workers, can help increase the availability of culturally competent care.

Incentives and Requirements

Federal, state, and local governments; payers; and providers represent a continuum when it comes to race and ethnicity data completeness, quality, and initiative. Some stakeholders have invested time and resources into improving their data. Others are interested, but not sure how best to proceed, and some have other priorities and/or fewer resources to devote to improving their data. As a result, a one size fits all approach will not work. Therefore, the federal government should use a combination of incentives and requirements to increase racial and ethnic data completeness and quality at the state and local level.

⑤ **OMB should require all federal program reports to include data stratified by race, ethnicity, and other demographics where feasible.**

Some reports such as the *National Healthcare Quality and Disparities Reports*; *Health, US*; and *Part C and D Performance Data Stratified by Race, Ethnicity, and Gender* all provide information stratified by race and ethnicity and other demographic characteristics. However, many federal program reports do not. In some instances, special reports have been issued, but that leads to less timely information and dependence on champions, luck, and political or external pressures to get the information needed to identify and monitor health disparities. Making the reporting of this data standard operating procedure will help ensure that it is more consistently available, will raise awareness about racial and ethnic health disparities, and can help spur improvement in the data. Using the data can also signal to stakeholders that the government is interested in this topic. It may also lead to more stakeholders looking at their data.

⑥ **HHS should require state and local health departments, Medicaid programs, public health, and human service programs to conduct an audit of their race and ethnicity data to identify information gaps and barriers to completion.**

Understanding where there are data gaps is critical for guiding efforts to address barriers and solutions and planning for the resources that are needed to fill data gaps. Smaller agencies like local health departments may need supplemental funding and technical assistance to achieve these goals. This should also include an audit of how the data are collected (e.g., self-report, or another method).

Education and Technical Assistance

Stakeholders consistently noted the lack of awareness or understanding of the guidelines and best practices regarding the collection of racial and ethnic information, discomfort among those asking individuals to indicate their race and ethnicity, and a lack of awareness on the part of the consumer all contribute to incomplete racial and ethnic data, as well as inaccurate data. Experts noted that in some cases health plans and systems key informants mistakenly believed that the Federal government or state laws or insurance regulations prohibited the inclusion of race and ethnicity questions in data collection efforts. Others were unaware that standardized data categories exist or were concerned that consumers would not provide the information. Clarifying what is allowable as well as best practices is a critical step in improving data completeness and quality.

(7) **HHS and other departments should support states through technical assistance and financial assistance to improve data systems and interoperability, as well as improved analytic and reporting capacity.**

Many departments and agencies work with states to administer their programs. For example, CMS has a long history of working with states through multiple avenues such as state grantee initiatives, the State Operations and Technical Assistance (SOTA) calls, and informational bulletins, CDC supports state departments of public health, HRSA engages with states on their maternal health programs, and USDA interacts with states through SNAP. As part of their interactions with states, the federal government could raise awareness about the need to improve race, ethnicity and other demographic data and provide tools, resources, and best practices to help states improve their data. Through these same programs, the federal government could provide additional resources to help states improve their data infrastructure. Medicaid allows states to receive a 90 percent match from CMS for state administrative activities related to the development of core health information exchange (HIE) services (e.g., designing and developing a provider directory, privacy and security applications, and/or data warehouses), public health infrastructure, electronic Clinical Quality Measurement (eCQM) infrastructure, and provider on-boarding. Nearly all states already participate in the program, but it is not clear if states are using any of these funds to improve their race and ethnicity data.

(8) **HHS should develop educational resources on the importance of asking an individual about their race and ethnicity, and resources on why it is important to answer the questions and how the information will be used. In addition, HHS should work with myriad stakeholder groups (e.g., providers, consumer and community-based organization, public health, etc.) to disseminate the information.**

Resources like the American Hospital Association (AHA) Health Research and Educational Trust Disparities Toolkit already exist to provide guidance for health systems on collection of race and ethnicity data and could be adapted for other stakeholders. These resources could be compiled, updated, and distributed to a wider audience with HHS endorsement. HHS should also issue guidance to clarify that federal regulations do not prohibit collection of race and ethnicity data. Doing so would address some of the perceived barriers to care that stakeholders reported have been posited as reasons for not collecting race and ethnicity data. While entities cannot require people to answer these questions, federal law does not prohibit asking for race and ethnicity data.

(9) **Include community voices in the development and dissemination of materials explaining why the information is collected, how it will be used, and why it is important to collect.**

Often consumers are unclear as to why they are being asked to provide information and unsure how the information will be used, making them more reticent to provide the information. The use of help text explaining why a question is being asked has been shown to increase response rates. Working with communities to understand their concerns and collaborating with them on the development and dissemination of resources can also help increase response rates and help ensure the response options reflect the diversity of the community.

Regulation

As noted above, multiple stakeholders expressed beliefs that one or more aspects of federal laws or regulations prevented them from collecting race and ethnicity data. Understanding what federal policies create real or perceived barriers to data collection—including but not limited to formal prohibitions—is a critical step in improving the data available in health programs. Moreover, as the range of stakeholders with interest in (and potential access to) health data grows with the proliferation of health apps, federal policy may need to expand to cover these domains as well.

10. **Congress should review and amend as necessary the Health Information Portability and Accountability Act (HIPAA), the Family Educational Rights and Privacy Act (FERPA), the Patient Protection and Affordable Care Act (ACA), and other data laws to encourage the collection and sharing of information across health, human and social services, including the justice system.**

    Despite recent efforts to improve data sharing, multiple stakeholders noted that this remains a challenge and will require congressional action to change.

11. **Improving privacy protections of data captured through health apps, such as increasing FTC's authorization since they manage the health apps.**

    An increasing number of apps make it easier for consumers to track their health, set goals and monitor progress towards meeting them. However, several interviewees suggested more needs to be done to improve data protections because many of the apps are not covered by HIPAA. Improving data protections could lead to increased consumer confidence and a greater willingness to share the information.

Conclusion

Though the COVID-19 pandemic has laid bare and intensified racial and ethnic health disparities, the current crisis has also brought renewed attention to these disparities. Improved data on race and ethnicity is not only essential to measuring the extent of current gaps but will play a critical role in addressing these challenges as well.

The federal government can provide essential support to these efforts, investing its resources in data system changes and education and technical assistance for expanding collection and use of race and ethnicity data. It can also increase incentives to collect and assess these data and, in cases, requiring that federal program participants do so. Finally, by reviewing existing regulation to assess where current policy may restrain (or create the appearance of prohibiting) collection of race and ethnicity data, the federal government can empower stakeholders to pursue these necessary efforts.