Using Race and Ethnicity Data to Advance Health Equity

Examples, Promising Practices, Remaining Challenges, and Next Steps

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There is widespread agreement that monitoring patients' health care access and quality by demographic categories such as race and ethnicity and using such data to develop effective interventions is essential to advancing health equity (American Hospital Association 2013; GIH and NCQA 2021a,b; Haley et al. 2022; National Academy for State Health Policy, Duke Margolis Center for Health Policy, and National Governors Association 2021; National Commission to Transform Public Health Data Systems 2021). Major efforts are underway in various sectors of the health care system to improve the completeness of individuals' self-reported race and ethnicity data. But little is known about the extent to which patient race and ethnicity data are being used to address inequities or about efforts to collect the race and ethnicity data of health care providers, which would also be informative in promoting health equity. Many stakeholders may remain skeptical about whether the potential benefits of complete and accurate data are worth the investments needed to improve data collection infrastructure and practices and build analytic capacity.

The landmark 2003 report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*, revealed shocking racial and ethnic disparities in access to and quality of health care (IOM 2003).

Among other findings, the study noted that the lack of standardized and systemwide collection of data on patient and health care provider (provider) race and ethnicity was one of the key barriers to understanding and eliminating racial and ethnic disparities in health care. Fast-forwarding to 2023, we find that many barriers to systematic race and ethnicity data collection identified in the *Unequal Treatment* report persist. Despite broad interest in reducing health inequities, many data collection efforts are still developing, and evidence of the use of data to advance health equity remains limited. Even many states, health plans, and health systems at the forefront of this effort lack complete, reliable, high-quality data on patients (let alone on providers) and are seeing limited reductions in health care disparities based on the use of such data to develop and implement health equity interventions.

Unequal Treatment at 20

This work is part of a series of publications that commemorates the 20th anniversary of the 2003 Institute of Medicine report, U*nequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. This report found that people of color received lower-quality health care than white patients, even when access-related factors were held constant. Two decades later, we still observe the same inequities, which has motivated thought leaders to imagine how to redesign the health care system so it works equitably.

To inform efforts to scale up race and ethnicity data collection and analysis, this brief draws on publicly available resources, interviews with leaders and analysts in the health care sector, and a series of case studies to share examples of progress and highlight key considerations, challenges, and promising practices in collecting and using demographic data to monitor and reduce inequities. For this study, we adopted the Robert Wood Johnson Foundation's (RWJF) definition of health equity which posits that "health equity means that everyone has a fair and just opportunity to be as healthy as possible."[1] Our key findings include:

- **Collection of individuals' race and ethnicity data to advance heath equity is happening, but it remains inconsistent and incomplete**. Though interest in data collection may be stronger than ever, many systemic barriers to collecting patient demographic data hinder greater progress.
- **Health care organizations are increasingly collecting a variety of other demographic and social needs data and using broader measures of access and quality**, recognizing that race and ethnicity data are important but insufficient to monitor and achieve health equity.
- **Collection and sharing of provider race and ethnicity data appears very limited.** Interest in collecting provider data for the purposes of addressing health inequities, such as through improving consumer access to culturally appropriate and effective care, is high. But we identified few examples of organizations making significant efforts to collect and share such data, heard about concerns about potential discrimination, and found that the current regulatory and policy environment is not supportive of such efforts.

- **Initiatives that use individual race and ethnicity data to advance health equity appear more limited**; most activity seems more narrowly focused on improving the collection of such data.
- **Public and private action could improve the collection and use of race and ethnicity data.** This could include greater pressure from federal and state governments as well as several organizational changes:
  - » *Federal and state actions* include: (1) providing requirements, guidance, and resources to support systematic and comprehensive data collection; (2) standardizing and aligning data to support its usability, and (3) implementing accountability, incentives, and consequences to support the use of data to reduce health disparities.
  - » *Institutional facilitators* to progress include: (1) securing and cultivating leadership support, (2) institutionalizing commitment to health equity within an organization, and (3) maintaining focus on the end goal when facing obstacles.

While our findings seem less than optimistic, key informants highlighted the importance of aggressively pursuing efforts to improve race and ethnicity data collection and use, indicating that the current sociopolitical context is more favorable than 20 years ago to sustain momentum and accelerate progress toward advancing health equity. In the remainder of this brief, we review key points in the history of race and ethnicity data collection over the last two decades, describe our research methods, detail key findings, and close with main policy and practice implications.

Brief History of Race and Ethnicity Data Collection in Health Care

When *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* was published in 2003, the committee summarized the data challenges, including that efforts to collect data were "unsystematic and inadequate to monitor the quality of care provided to racial and ethnic minorities," and provided several recommendations to help increase the collection and reporting of racial, ethnic, and primary language data (IOM 2003). In the years that followed, data collection efforts largely remained unsystematic, and many of the barriers to collection persisted, leading to workarounds such as the development of imputation models for race and ethnicity data (Elliott et al. 2008; Haas et al. 2019). Reporting of stratified data increased with the publication of the *National Healthcare Disparities* reports from the Agency for Healthcare Research and Quality;[2] however, many of the quality and access indicators used in the earlier reports could not report data for all racial and ethnic populations.

In 2009, the National Academies published *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*, which encouraged the collection of granular race and ethnic data and provided recommendations for improving the collection and use of the data across the health system (IOM 2009). Like *Unequal Treatment*, this report called for including race, ethnicity, and language data in accreditation standards and performance measurement.

Race, ethnicity, and other demographic data collection received a boost with the passage of the Affordable Care Act. Section 4302 of the law required the US Department of Health and Human Services (HHS) to develop and implement data standards for race, ethnicity, sex, primary language, and disability (HHS 2011). The HHS data standards included subgroups for Hispanic ethnicity and two additional race categories: (1) Asians and (2) Native Hawaiians and Pacific Islanders. Although they were not universally adopted, they were used on Marketplace applications and numerous surveys.

Race and ethnicity data collection efforts received another boost in 2020 with the COVID-19 pandemic and the racial justice movement sparked by unjustified killing of a Black man—George Floyd—by a white police officer, as the country became very aware of the deep and persistent racism and inequities people of color experience in areas such as health and health care, income, employment, and education.[3] At federal and state levels, efforts to collect racial and ethnic data have increased, as have efforts to incorporate an equity lens into quality improvement and value-based payment. The Biden Administration issued executive orders to address the data gaps and COVID-19 disparities.[4] The Office of Management and Budget is proposing to update the federal data standards for race and ethnicity,[5] and the Centers for Medicare & Medicaid Services is advancing equity through quality improvement and payment reform.[6]

In the 20 years since *Unequal Treatment* was published, there have been myriad efforts to assess and increase the completeness and quality of racial, ethnic, and other demographic data across the health system (GIH and NCQA 2021; Haley et al. 2022; SHVS 2022); and a growing number of reports present health and health care quality data stratified by race and ethnicity.[7] These reports have shown some improvements in race and ethnicity data completeness, but less is known about whether and how health care providers and systems are *using* data to eliminate health disparities and advance health equity.

Methods

Between late 2022 and early 2023, we conducted an environmental scan and 13 semistructured interviews with both national experts on race and ethnicity data collection and use and health care representatives (see table 1) to gain their perspectives on patient and provider race and ethnicity data collection and analysis. The goal of our work was to highlight actionable examples of collecting and using data to advance health equity.

We began the study by conducting an environmental scan to identify promising data collection and analysis efforts within states, Marketplaces, Medicaid, health plans, and hospitals and health systems. Then we conducted seven interviews with policy experts to ask their perspectives on efforts that have been making strides around race and ethnicity data. Topics discussed included overarching perspectives, key considerations, barriers, facilitators, and policy recommendations to strengthen data collection and analysis. The RWJF-funded community advisory board focused on health equity informed the key research questions and direction of the project.

Based on the scan of publicly available information and input from national experts and advisory board members, we selected three data initiatives to study in more detail: Michigan's Medicaid program and an associated managed care plan, Oscar Health (a health insurance company based in New York), and Sutter Health (a health system in northern California). We selected these initiatives to understand data collection from a variety of perspectives (state Medicaid agency/Medicaid managed care organization, health plan, and health system) and because they were identified by at least one national-level stakeholder as having enthusiastic and engaged involvement in using (or planning to use) individual or provider race and ethnicity data to reduce inequities. In addition, we aimed to include data initiatives that had not yet been extensively discussed in the literature. Key features of the case study data initiatives are highlighted in table 1.

TABLE 1

Case Study Initiatives at a Glance

	Michigan Medicaid	Oscar Health	Sutter Health
Organization type	Medicaid agency	Marketplace health plan	integrated health system
Populations and geographic areas served	2.3 million members in Michigan	1 million members across 20 states	3 million patients in 22 counties in Northern California
Individual self-reported race and ethnicity data collection mode and completeness	race and ethnicity data from Medicaid application; available for slightly over 90 percent of members; data shared with health plans	Marketplace application, health risk assessment, member onboarding, and member portal collection; race and ethnicity data available for about 70 percent of members	patient medical records during patient registration, patient portal collection; race and ethnicity data available for about 85 percent of patients
Race and ethnicity data analysis and reporting	stratified public reporting of HEDIS quality measures published in annual health equity reports since 2011	analysis of stratified HEDIS measures by race and ethnicity for particular clinical disparities; collection and analysis of race/ethnicity data for Annual Cultural Needs and Preferences Report	developed Health Equity Index, which can identify disparities using real-time hospital encounter data for a specific diagnosis stratified by patient demographic data; published research on disparities
Example of interventions to close disparities informed by data analyses	developed Medicaid Health Plan Low Birth Weight project to promote health equity through pay-for-performance initiatives	developed clinical interventions to reduce disparities in diabetes management among Hispanic/Latinx members and improve colorectal cancer screening rates among Asian American members	developed clinical interventions to reduce disparities, including asthma management program for Black patients and diabetes clinics for Hispanic/Latinx communities

	Michigan Medicaid	Oscar Health	Sutter Health
Noteworthy innovations	Medicaid-managed care contracts include incentives for health plans for closing racial and ethnic disparities across five measures.	Culturally Competent Care program includes an effort to collect and report physician race and ethnicity data to support member choice of culturally relevant providers.	Institute for Advancing Health Equity is tasked with translating disparities research into health equity interventions.
Other data collected to monitor disparities	collecting gender, primary language, and disability status data	collecting member language and sexual orientation and gender identity data; leading efforts to collect and share provider race and ethnicity data with members but facing obstacles, with only 10–15 percent of providers' race and ethnicity data available	collecting patient language and housing insecurity data pursuant to California legislation working on developing standard approaches for collecting other social needs and SOGI data systematically in EHRs; limited data on provider race and ethnicity due to confidentiality of contracted providers' records

Sources: Authors' analysis of key informant interviews.
Michigan Medicaid sources: Michigan Department of Health and Human Services, "Medicaid Health Equity Reports,", accessed June 5, 2023; Michigan Department of Health and Human Services, "Michigan Department of Health and Human Services Comprehensive Quality Strategy 2020–2023," December 17, 2020; NORC, "The State of the Collection of Race, Ethnicity, and Language Data in Medicaid," February 2022, Chicago: NORC at the University of Chicago;
Sutter Health sources: Alice Pressman, Stephen Lockhart, John Petersen, Sarah Robinson, Maria Moreno, and Kristen M. J. Azar, "Measuring Health Equity for Ambulatory Care Sensitive Conditions in a Large Integrated Health Care System: The Development of an Index," *Health Equity 3*, no. 1: 92–98, 2019, https://doi.org/10.1089/heq.2018.0092; Sutter Health, "Conducting & Facilitating Research," April 22, 2022; https://vitals.sutterhealth.org/health-equity/research/; Sutter Health, "Community-Based Solutions," September 1, 2022, https://vitals.sutterhealth.org/health-equity/community-based-solutions/; California State Legislature, Senate Bill No. 1152 Chapter 981, accessed June 5, 2023, https://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=201720180SB1152;
Oscar Health sources: Oscar Health, "Tackling Health Care Disparities through Culturally Competent Care,"accessed June 5, 2023, https://www.hioscar.com/blog/tackling-health-care-disparities-through-culturally-competent-care.
Notes: EHR = electronic health record; HEDIS = Healthcare Effectiveness Data and Information Set. SOGI = sexual orientation and gender identity.

We then conducted six interviews with representatives of these case study organizations: two interviews each with representatives from Sutter Health and Oscar Health, and one interview each with representatives from the Medicaid program and a Medicaid managed care plan from the state of Michigan. Interview topics included motivations and goals for race and ethnicity data collection efforts, processes and infrastructure for data collection, assessment of quality and strategies to improve the completeness of self-reported demographic data, measures of access and quality, efforts to use data to eliminate disparities, and the remaining challenges and changes needed to support data collection and use in health equity interventions. The research team conducted a thematic analysis of interview notes to derive common themes and key takeaways from the qualitative data.

The study has several limitations: we conducted interviews with a small number of informants, so some important perspectives and ideas might have not been captured, and perspectives presented here do not represent those of all organizations or states collecting and using data to address health inequities. In addition, our study specifically focused on race and ethnicity data collection because of large evidence of racial and ethnic disparities in health care (IOM 2023). However, we (and our key informants) recognize that disparities occur in other areas (e.g., rural vs. urban populations, for people with disabilities, and by sexual orientation/gender identity), and other demographic and socioeconomic data must be collected and used to fully understand and reduce health and health care disparities.

Findings

Below we describe findings from our policy scan and key informant interviews on efforts to collect and use race and ethnicity data to address health care inequities, organized into five major takeaways:

- The collection of individuals' race and ethnicity data remains inconsistent and incomplete.
- Other types of data and better health equity measures are needed to understand and reduce disparities.
- The collection and sharing of provider race and ethnicity data is very limited.
- Initiatives to use race and ethnicity data analysis to advance health equity appear more limited than data collection.
- Public and private action could improve collection and use of racial and ethnic data.

The Collection of Individuals' Race and Ethnicity Data Remains Inconsistent and Incomplete

According to key informants, the collection of individuals' race and ethnicity data by health care entities to understand and address heath inequities is accelerating, particularly since the COVID-19 pandemic. But they largely agreed that, overall, race and ethnicity data remain inconsistent and incomplete because many barriers to collecting patient demographic data identified in the *Unequal Treatment* report still exist 20 years later.

VARIATION IN RACE AND ETHNICITY DATA COLLECTION COMPLETENESS AND QUALITY

Key informants we interviewed indicated that despite widespread interest in reducing racial and ethnic disparities in health care access and quality, many state governments, health systems, health insurers, providers, and others are only beginning to systematically collect or improve the collection of self-reported race and ethnicity data of individual members/patients for the purpose of understanding and addressing health inequities. They described a wide array of modalities and settings of current data collection of self-reported race and ethnicity—including at health plan enrollment (such as in Medicaid or Marketplace applications), during clinical encounters at health centers or with other providers (recorded in electronic health records [EHR] and health information exchange systems) and plan-based data collection through care management or health risk assessments, and during member onboarding processes or ongoing through plans' patient portals or apps. Several key informants noted the lack of evidence for which collection strategies are most effective and indicated there are pros and cons of various collection modes and different needs for various modes (e.g., online vs. on paper, individually reported vs. with assistance, at the time of plan enrollment vs. later). But there was widespread agreement that self-reported race and ethnicity data was the industry gold standard, as opposed to identity as observed by others or allocated using imputation methods.

Overall, national experts described the quality and completeness of individuals' self-reported race and ethnicity data as quite variable across states and entities or, as described by one expert, as "very, very mixed." The variation described in interviews is consistent with other evidence. For instance, recent data show state race and ethnicity collection rates below 50 percent in some states' Medicaid programs, while being above 90 percent in others (MACPAC 2022; Melendez et al. 2022).[8] Another key informant cautioned that data completeness (for how many individual's information is available) and accuracy (whether it is self-reported using a categorization the individual believes is correct for them) should not be confounded. In fact, this informant believed that asking about race and ethnicity respectfully, with an opt-out option, could generate data that has *more* missing values. But they believed the responses would be more authentic and more accurate because data reflect respondents' choices in sharing their identity.

PERSISTENT BARRIERS

Consistent with prior research, key informants described a range of barriers to completing the universal collection of patients' self-reported race and ethnicity data. These barriers include individuals worrying about sharing their identities to a system (such as state agency or health plan) they consider untrustworthy, a lack of community involvement in the development of data collection processes, limited efforts to share data across organizations and sectors (including people being weary of their data being shared with others without their explicit permission), limited prioritization of collection within organizations, and a dearth of research on effective uses of such data to reduce inequities (American Hospital Association 2013; GIH and NCQA 2021a,b; Haley et al. 2022; National Academy for State Health Policy, Duke Margolis Center for Health Policy and National Governors Association 2021; National Commission to Transform Public Health Data Systems 2021). Further details about these barriers are in box 1.

BOX 1

What Are Major Barriers to Progress in Collecting Individual Race and Ethnicity Data?

Despite some progress with efforts in the collection of self-reported race and ethnicity in health care settings across the country, key informants identified a range of barriers to further progress in collecting and using individual race and ethnicity data and several unresolved questions.

Multidimensional lack of trust. Lack of trust has long been identified as a key concern in individuals' unwillingness to share data with institutions, including health insurers and governments.[1] But in interviews. we heard insights on mistrust in other directions, such as providers not wanting to share their patients' data with health plans, not trusting efforts to collect provider-level demographic data, and organizations not trusting the validity of each other's data. As one key informant indicated, state officials tend to prefer data collected by state-run programs and often are skeptical of data collected by health plans or providers because of fear that those data are not self-reported by member or patients.

Lack of community input. Several key informants shared that community engagement on the issue of race and ethnicity data collection and use may be increasing but is not yet sufficient to overcome mistrust. In state Medicaid agencies, deliberate efforts to more effectively engage Medicaid members were described as increasing in the post-COVID, post-George Floyd era, but an explicit focus on data issues in community engagement was generally described as quite limited.

Lack of consistency and public reporting. Some key informants expressed interest in coordinated data systems, described as "collecting once, using many times." However, the lack of consistency in data standards such as when different collection systems use different racial and ethnic classifications hinders the creation of such a system. Furthermore, while many (though not all) key informants reported widespread confidence in understanding the extent of data collection or lack thereof in Medicaid, little is known about race and ethnicity data collection in other parts of the health care system. For instance, some key informants believed that some health care organizations (such as health plans and hospitals) were collecting and using individual-level race and ethnicity data for internal/business decisionmaking but not necessarily publicizing their efforts.

Lack of data sharing and interoperability across organizations. Moreover, efforts were described as siloed, that is as being very different and uncoordinated across entities, including using different racial and ethnic classifications in different collection systems, collecting information on the same people but not sharing the data, and lacking interoperability in terms of data structure/format across organizations or even between departments of an organization. Even when data could be shared, as in the case of state health information exchanges, the lack of systems to designate its source and providence (when and how it was collected) would limit its usefulness.

Limited prioritization of race and ethnicity data. While race and ethnicity data categories have been included on health insurance applications, patient records, and other health care forms for decades, until recently, little attention has been paid to ensuring the accuracy and completeness of these data. Lack of enforcement of existing reporting requirements, limited resources dedicated to patient/member and staff education and data infrastructure, and limited evidence on what strategies work to improve self-reporting of race and ethnicity data explain why many health care organizations today are still primarily focusing on how to improve their data collection efforts.

Perceived lack of evidence on effective interventions. Some key informants reported that one reason for inconsistent prioritization of data collection efforts across states and organizations was related to not knowing how to address identified disparities at either the individual or population level. As one provider stated: "Even if I know [where inequities exist], well, how do I need to do things differently in my daily practice to close gaps or to improve outcomes in my population?" This highlights the need for more research into effective health equity interventions and increased awareness of effective interventions through the dissemination of best practices and tools to support organizations in implementing proven interventions.

Sources: Authors' analysis of key informant interviews; [1] Jennifer Haley, Lisa Dubay, Bowen Garrett, Clara Alvarez Caraveo, Ilyse Schuman, Katy Johnson, Jason Hammersla, James Klein, Jay Bhatt, David Rabinowitz, Heather Nelson, and Becca DePoy, "Collection of Race and Ethnicity Data for Use by Health Plans to Advance Health Equity: Opportunities, Barriers, and Solutions,": Urban Institute, 2022, https://www.urban.org/research/publication/collection-race-and-ethnicity-data-use-health-plans-advance-health-equity.

Other Types of Data and Better Health Equity Measures Are Needed to Understand and Reduce Disparities

Key informants repeatedly recognized that race and ethnicity data are important but alone insufficient to understand disparities and identify effective interventions and policy solutions to achieve health equity. People experiencing or at high risk of disparities often have other marginalized identities and characteristics that must be identified to develop the most impactful interventions. Health care organizations are also increasingly collecting a variety of other demographic and social needs data and looking to identify broader measures of access and quality to identify disparities.

Language, social needs, and identity are frequently cited as priority data. Key informants noted that while race, ethnicity, and languages spoken have been prioritized in demographic data collection, the focus on understanding and collecting other demographic and socioeconomic data is more recent. It is not surprising, therefore, that these data are less complete than race and ethnicity data (NASEM 2016). Most frequently, key informants reported efforts to screen patients and members on their health-related social needs (HRSN) such as food insecurity, housing stability, or transportation needs. For example, Medicaid-managed care programs are increasingly requiring that health plans identify and address members' HRSNs (Crumley et al. 2018; Shin et al. 2021). Hospitals and providers are also increasingly screening their patients for unmet social needs (Fraze et al. 2019). Key informants lamented that though HRSN screenings occur more frequently than ever before, data are not necessarily systematically collected, analyzed, and reported.

Similarly, there is a growing desire to collect sexual orientation and gender identity (SOGI) data (SHVS 2021),[9] but key informants acknowledged these data are rather sensitive and that more guidance, education, and training are needed to support culturally effective practices in their collection. For example, Oscar Health's patient portal app is available in Spanish and includes a "My Identity" feature that allows members to select how they want to identify and their pronouns.[10] Furthermore, some informants noted the importance of not only collecting HRSN, SOGI, and other data but using that data effectively to address people's care needs and preferences.

Insufficient measures of disparities in access and quality. Importantly, assessing inequities in health care access and quality by race and ethnicity requires not just race and ethnicity data but high-quality, useful indicators of access and quality. Since 2011, Michigan has released a series of annual reports on health equity, assessing a range of Healthcare Effectiveness Data and Information Set (HEDIS) measures stratified by race and ethnicity, as part of the state's Medicaid Health Equity Project, making the state a leader in sharing disparities in quality measures over time.[11] However, several informants described many existing measures of access and service use as insufficient. They said that data sources like Consumer Assessment of Healthcare Providers and Systems (CAHPS) and HEDIS measures are often used in assessing health equity, but that much broader quality and access measures are needed. Ideally, incorporating community input into identifying meaningful measures that assess the outcomes is most important to consumers. Another informant expanded on this, saying that both process and outcome measures, at both system and individual levels, are needed, because the context will dictate which measures of access and quality are most important. As described by another key informant, a broad definition of access and quality would also include "accessibility," "appropriateness," "affordability," and "approachability" as well as discrimination experiences. In particular, we heard several ideas for broader access and quality measures, including the following:

- ***Access to care*** measures such as distance to care, appointment wait times, language access, and out-of-network use.
- ***Patient experience and satisfaction*** measures that reflect the challenges and experiences that are most important to patients. For instance, the Blue Cross and Blue Shield of North Carolina Foundation is developing a health equity index measuring not just access and affordability but incorporating community perspectives on components of the index, including social drivers of health and patient experience, and Sutter Health's collection of race and ethnicity data will be coupled with patient experience measures to more completely measure health inequities beyond existing measures.[12] Atrium Health, which has devoted efforts to improving the collection of race, ethnicity, and language data and collects such data from over 97 percent of members, employs a scorecard approach called a "demographic data wall" to share quality and outcome measures that include staff and patient experience indicators. Relatedly, some key informants discussed expanded measures of provider cultural competency; as one stated, "There's also that question of providers'…cultural competency and the race/ethnicity of providers compared to the population they're serving. You know that those are two big aspects and…what's the right metric? What's the indicator of quality related to that? Is it simply saying that the ethnicity or language of the provider matches the patient, or is it something more?"
- ***Health outcomes*** including measures relying on analysis of claims and encounters data and using clinical reviews. One key informant indicated their organization is examining quality metrics measuring rates of health conditions that are known specifically to be priorities for populations they are serving, like hypertension, diabetes, and cancer. Atrium Health has used such data to develop new initiatives such as its "For All" Health Equity Colorectal Cancer Screening Goal to reduce disparities in colorectal cancer screenings.[13]

The Collection and Sharing of Provider Race and Ethnicity Data Is Very Limited

Though some information is available on the race and ethnicity of health care providers overall,[14] there appears to be a much more limited, almost nonexistent, collection of data on race and ethnicity of individual providers to advance health equity, according to key informants and current literature. In interviews with national experts, we identified only one example of a health plan—Oscar Health—that rose as a leader in its efforts to collect and make available provider race and ethnicity data (box 2). The Centers for Medicare and Medicaid Services (CMS) asks providers about their race, ethnicity, language(s) spoken in their practice, and whether their practice is accessible for someone with a disability through the National Plan and Provider Enumeration System (NPPES), but the data are voluntary and only asked when a provider chooses to update their information or enroll as a Medicare provider.[15]

In interviews, we heard that sharing providers' race/ethnicity and language with patients could support greater concordance, as patients could select providers who identify similarly or speak the same language; allow for assessing the cultural and linguistic capacity of provider networks; and meet accreditation requirements that may increasingly require information on providers' identities (Ma, Sanchez, and Ma 2019). But key informants indicated that health plans, health systems, and Medicaid agencies do not appear to prioritize collecting and sharing provider race and ethnicity data, as most who are prioritizing race and ethnicity data collection are largely focusing on patient or member data. In fact, improving completeness and reliability of provider race and ethnicity data was often described as on a longer time horizon than individual race and ethnicity data, according to some key informants.

While there appears to be growing interest in more comprehensive provider race and ethnicity data, key informants noted multiple barriers to collecting and sharing such data. These included trust issues similar to those underlying challenges with individual data, relating to a history of people misusing data and concerns among providers that being identified by their race and ethnicity will result in discrimination by patients. Moreover, logistical challenges and interoperability concerns were identified as major barriers, such as those related to confidentiality of employment records, technical limits in how to share identity information on physicians in provider directories, inconsistencies in categorizations and extent of data collection across organizations, and lack of willingness for sharing between entities such as health systems, provider associations, and regulatory bodies with health plans or consumers.

BOX 2

Efforts to Collect Provider Race and Ethnicity: Oscar Health

According to key informants, Oscar leadership has always prioritized member experience and focused on strategies to best meet the unique needs of their diverse membership. The Culturally Competent Care (CCC) program was born from an observation that members do not have adequate access to doctors who look like them, share the same culture, or speak the same language.[1] The racial and ethnic health disparities that were spotlighted during the COVID-19 pandemic and the murder of George Floyd further reaffirmed and accelerated Oscar's efforts to develop culturally effective physician networks, where Care Guides (or care navigators) can help members find providers by their preferred cultural background, including by race and ethnicity.[16] Through robust advocacy and engagement with health systems and provider groups, state regulatory agencies, and provider associations, the Oscar team learned that physician race and ethnicity data are not systematically collected, and that there are numerous regulatory and privacy barriers to obtaining those data if they do exist. Today, Oscar has race and ethnicity data on only about 10–15 percent of its contracted physicians.

However, Oscar has had some success in making the culturally competent physician network a reality in its Houston, Texas, market where the plan launched an outreach campaign to contract with more racially and ethnically diverse physicians, using existing networks and cold calls to providers identified via internet searches. Though the Oscar team recognizes this is not a scalable strategy on a national level, this experience taught them that personal conversations with physicians can be an effective way to build trust and educate physicians on why their race and ethnicity information is important to share. Oscar continues to search for viable options for sharing physicians' race and ethnicity data (and other helpful information such as competency in LGBTQIA+ care) in provider directories. Oscar is also planning to implement periodic cultural effectiveness trainings for all its contracted providers and develop a survey to learn more about member experiences with culturally effective care.

Sources: Authors' analysis of key informant interviews;
[1] "Tackling Health Care Disparities through Culturally Competent Care," Oscar Health, accessed September 12, 2023, https://www.hioscar.com/blog/tackling-health-care-disparities-through-culturally-competent-care.

Initiatives to Use Race and Ethnicity Data Analysis to Advance Health Equity Appear More Limited Than Initiatives to Collect Data

Overall, key informants' perceptions were that in many states and organizations, the *collection* of race and ethnicity data—let alone the *utilization* of such data—is only just beginning. In fact, even in organizations with robust data collection and assessment of health disparities by race and ethnicity, the examples of *using* such data to develop interventions that could reduce health inequities and build an evidence base of effective solutions are more limited. However, such efforts appear to be growing.

Most organizations appear not yet to be using data to address disparities, but a few are. For example, Aetna and Blue Cross Blue Shield of Massachusetts share disaggregated data and solutions they are developing to reduce inequities, and a growing number of states are using managed care contracting to require plans to address health disparities (Bailit Health 2022). Though Michigan has been analyzing and posting annual reports on health disparities in its Medicaid program since 2011, it recently began developing initiatives aimed at reducing those disparities. Michigan Medicaid ties managed care plan reimbursement to equity, using data shared with plans collected by the state at the time of enrollment. Plans can receive performance bonuses (totaling $29 million in fiscal year 2022) for reducing race/ethnicity disparities across five measures of care utilization (HbA1c testing, cervical cancer screening, well-child visits, postpartum care, and chlamydia screening).[17] According to state officials, previous managed care contracts included requiring plans to implement Performance Improvement Projects to reduce disparities (Michigan Department of Health and Human Services 2020).

Oscar Health representatives shared that the plan uses annual health equity and population health analyses to identify disparities and inform interventions. Based on these data, Oscar recently implemented two clinical interventions to specifically target racial and ethnic disparities. One of these interventions has focused on improving diabetes control measures in Hispanic/Latinx members, using a multipronged approach that includes culturally effective messaging and care management for diabetes patients, as well as outreach and education to providers to share data on racial and ethnic disparities among their patient populations. Oscar also provided these data to health system leadership to spotlight potential unconscious bias among providers. Another intervention has focused on improving colorectal cancer screening rates in the Asian American population using a similar approach of improving language access to preventative education among both members and their providers and providing in-home screening tools to members. While data are still being gathered and analyzed to determine if these interventions were successful in reducing disparities, these examples show how data can be effectively used to spur action. Through its health equity and cultural competency efforts, Oscar earned NCQA's Multicultural Health Care Distinction in California.[18]

Similarly, Sutter Health has thus far largely focused on examining disparities in its patient population but, according to key informants from the organization, the system is now planning to invest more heavily in developing and testing health equity interventions to build a more robust evidence base for what works, building on earlier efforts. In 2016, Sutter Health developed a first-of-its-kind metric known as the Health Equity Index (HEI) to effectively identify health outcome disparities in its system, using real-time hospital encounter data for specific diagnoses which can be stratified by patient demographic data. HEI has been instrumental in identifying disparities and informing the system's efforts to close them. For example, HEI data revealed higher-than-expected rates of emergency visits for asthma among African American patients, which led to the development of a tailored asthma management program for African American patients. In addition, as part of its pandemic response, Sutter developed a COVID-19 Vaccine Equity Index to effectively direct outreach and resources to communities that were at high risk of COVID-19 burden disease but had low vaccination rates.[19] In December 2020, Sutter Health launched the Institute of Advancing Health Equity to institutionalize and move forward its longstanding efforts to identify health care disparities in its network.[20] These efforts benefit from the guidance of an advisory council consisting of executive leaders from across the health care system to provide input on how to incorporate data science with clinical practice and operations and ensure the research is actionable. The advisory council meets every quarter. In addition, the Institute engages an external advisory committee of national-level experts that meets twice a year to provide input on potential health equity interventions. Key informants at Sutter Health noted that they are exploring ways to partner with patients and community members more effectively in health equity initiatives, as well as how to align with broader public health efforts.

Public and Private Action Could Improve Collection and Use of Racial and Ethnic Data

Consistent with prior research on best practices for data collection (Centers for Medicare & Medicaid Services 2022), key informants highlighted several strategies they thought could contribute to higher response rates and higher quality of self-reported race and ethnicity data (box 3). Likely, multiple strategies are needed at the same time to strengthen the completeness and accuracy of data being collected. Similar to recommendations in other studies (GIH and NCQA 2021a), key informants suggested that greater pressure from federal and state governments as well as several institutional actions could facilitate the widespread adoption of these promising strategies and help improve and sustain collection and analysis of racial and ethnic data to develop, implement, and evaluate health equity interventions.

BOX 3

Emerging Strategies to Improve Completeness and Accuracy of Self-Reported Race and Ethnicity Data

Engaging and educating patients. Overall, key informants repeatedly emphasized the importance of sharing with individuals the reason for asking about their race and ethnicity, what one described as: "giving them direct real answers about how the data may be used, in ways that they can see that there may be some potential benefit to [sharing] these data, if not to themselves, to the program overall or to other people." For example, the Henry Ford Health's "Why We Ask" campaign and Kaiser Permanente's efforts were mentioned as examples of communication from health systems to patients to encourage race and ethnicity data reporting.[1] Efforts in New York's Marketplace program to explain the rationale for collecting race and ethnicity as part of the application process were credited with increasing response rates.[2] Overall, we heard of a pressing need to identify effective ways to include people whose data are being collected when developing data collection and analysis strategies. For example, the Oregon Health Authority's guide for collecting demographic data includes tips and resources for authentically engaging communities in data efforts.[3]

Training frontline staff. Consistent with research evidence (Vega Perez et al. 2022), key informants emphasized that people assisting patients in health care settings and applicants for health insurance coverage need to be properly trained to understand why self-reported data are important, why they should avoid "guess[ing] a person's identity", and how to use standardized and culturally effective approaches to encourage people to respond to demographic questions. For example, the New Jersey Hospital Association and Health Research and Educational Trust of New Jersey identified barriers to race, ethnicity, and language data collection at hospitals and began work decades ago to standardize race and ethnicity categories and incorporate staff training to improve data collection practices.[4] Along with extended race and ethnicity categories and vetted multilingual information, Denver Health found that staff training led to higher completion rates of self-reported race and ethnicity data.[5] Sutter Health developed comprehensive guidance and conducted system-wide training of staff as part of their race and data collection efforts.[6] Key informants at Sutter Health believe that attention to patient communications and staff training likely contributes to the high response rates of race and ethnicity. A previous study examining data entry of patient demographic information found high levels of accuracy (92–97 percent).[7] And Michigan's Medicaid officials cited its strong community health worker partnership as one possible reason for their relatively high level of data completeness and quality.

Adopting patient-friendly data collection procedures that treat people with autonomy and respect. Strategies mentioned by key informants to show respect and build trust include allowing people to opt-out of questions, using categories that align with people's identities, and including in data collection processes an option for a person to change their categorization. For instance, Oscar Health representatives shared that members can use their plan's patient portal app to directly self-report or verify their racial/ethnic identification or to change it if their identity shifts.

Investing in building and maintaining infrastructure. Key informants also noted the importance of building, maintaining, and improving technology and infrastructure that supports data collection and analysis. For example, Sutter Health added and expanded patient race, ethnicity, ancestry, and language data fields in the medical records during an EHR platform upgrade. According to an interviewee from the organization, this was "a huge technological lift because at that time there wasn't as much appreciation for why … these data are helpful to have." The EHR updates were accompanied by an extensive education campaign to "socialize" leadership and staff on the importance of collecting patient self-reported race and ethnicity data. Today, Sutter Health estimates about 80–85 percent completeness of patient race and ethnicity data. Similarly, informants in Michigan believed the state Medicaid information systems and data capture processes greatly facilitate the high quality of their data. The completeness and accuracy of Michigan's data on race and ethnicity of enrollees is considered of "low concern," with fewer than 10 percent of responses missing.[8]

Using existing resources. Our scan also identified several toolkits that can help institutions ramp up data collection efforts, including the following:

- American Hospital Association, "Equity of Care: Toolkit for Eliminating Health Care Disparities," 2015, https://www.aha.org/system/files/media/file/2020/09/equity-of-care-toolkit-eliminating-healthcare-disparities.pdfhttps://www.aha.org/system/files/media/file/2020/09/equity-of-care-toolkit-eliminating-healthcare-disparities.pdf.
- California Health Care Foundation, "A Toolkit to Advance Racial Health Equity in Primary Care Improvement," 2022, https://www.chcf.org/publication/toolkit-racial-equity-primary-care-improvement/.
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- Washington State Hospital Association, "Race, Ethnicity, and Language Resources," 2021,http://www.wsha.org/wp-content/uploads/REaL-Data-Collection-Resources_WSHA-2021.pdf.

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[5] Nancy Wittmer, Maria Casaverde Marin, Cory Hussain, Ann Boyer, Rebecca Hanratty, Laura Jean Podewils, and Romana Hasnain-Wynia, "A Health System's Experience with Inclusive Race and Ethnicity Data Collection, And the Need for Data Equity Principles," *Health Affairs Forefront*, June 2, 2023;

[6] Institute for Diversity and Health Equity, "An Analytical Approach to Advancing Health Equity," (Sacramento, CA: Sutter Health, 2019), https://ifdhe.aha.org/system/files/media/file/2020/05/Sutter%20Health%20EOC%20Case%20Study.pdf;

[7] Kristen M. J. Azar, Maria R. Moreno, Eric C. Wong, Jessica J. Shin, Christy Soto, and Latha P. Palaniappan, "Accuracy of Data Entry of Patient Race/Ethnicity/Ancestry and Preferred Spoken Language in an Ambulatory Care Setting," *Health Services Research*, no. 47 (2012): 228–40, https://ifdhe.aha.org/system/files/media/file/2020/05/Sutter%20Health%20EOC%20Case%20Study.pdf;

FEDERAL AND STATE POLICIES

As summarized in table 2 and explored in further detail below, key informants suggested that federal and state policymakers could better support race and ethnicity data collection and analysis by using the following tools and strategies: (1) providing requirements, guidance, and resources to support systematic and comprehensive data collection; (2) standardizing and aligning data to support its usability, and (3) implementing accountability, incentives, and consequences to support the use of data to reduce health disparities.

TABLE 2

Federal and State Strategies to Support Race and Ethnicity Data Collection and Use

Needed interventions	Recommended federal and state actions
Requirements, guidance, and resources to support systematic and comprehensive data collection	▪ Requiring that health care programs report outcomes stratified by race, ethnicity, language, and other demographic characteristics ▪ Providing guidance, tools, technical assistance, and training to health care stakeholders ▪ Allocating adequate funding to support infrastructure and technical assistance for effective data collection
Standardization and alignment of data to support usability	▪ Developing and implementing clear and consistent data standards on race and ethnicity categories and other demographic and socioeconomic characteristics ▪ Aligning existing data sources and facilitating efficient and secure exchange of information
Accountability, incentives, and consequences to support the use of data to reduce health disparities	▪ Encouraging health care entities to embed health equity in their culture and operations ▪ Continuing to develop appropriate accountability mechanisms through public reporting and incentives and/or consequences tied to health equity measures ▪ Promoting evidence-building by providing technical assistance and allocating financial resources for the evaluation of interventions designed to reduce health disparities ▪ Requiring that patients and communities are meaningfully involved in designing, implementing, and evaluating health equity interventions

Source: Key informant interviews.

Providing requirements, guidance, and resources to support systematic and comprehensive data collection. Many key informants noted that federal and state requirements and mandates can be effective in ensuring that health care entities prioritize and invest resources in collecting race and ethnicity data and other information needed to identify and address health disparities. However, several emphasized that federal and state policymakers also must provide guidance and financial

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[8] SHADAC, "Race/Ethnicity Data in CMS Medicaid (T-MSIS) Analytic Files: 2020 Data Assessment," 2023, https://www.shadac.org/news/data-assessment-raceethnicity-tmsis; Ruben D. Vega Perez, Lyndia Hayden, Jefri Mesa, Nina Bickell, Pamela Abner, Lynne D. Richardson, and Ka Ming Ngai, "Improving Patient Race and Ethnicity Data Capture to Address Health Disparities: A Case Study From a Large Urban Health System." *Cureus* 14 no. 1 (2022): e20973. https://doi.org/10.7759/cureus.20973.

resources to build the capacity, infrastructure, and capabilities health care organizations need to collect race and ethnicity data effectively and efficiently. Actions federal and state policymakers can take to ensure data are consistently and systematically collected in health care programs include:

- **Requiring that health care programs report outcomes stratified by race, ethnicity, language, and other demographics**. Federal action has been identified as a need before (GIH and NCQA 2021a), and requirements to report stratified data are growing, such as a proposed CMS rule to make reporting of adult and child quality measures mandatory for states beginning in 2024 which would phase in reporting of measures by characteristics such as race and ethnicity, age, disability status, and rural versus urban status.[21] State governments can also implement laws that require the collection and reporting of patient demographic data by health plans and providers, as has been done in Connecticut for example.[22] Furthermore, several key informants noted that state and federal policymakers should consider ways in which public reporting of provider race and ethnicity and languages spoken could be achieved, such as, for example, requiring this information as part of licensing or contracting with health plans. Other options could be making disaggregated reporting required as part of state hospital community benefit reporting laws or as part of certificate of need processes. However, such a plan may need to also balance providers' concerns about discrimination.
- **Providing guidance, tools, technical assistance, and training** to health care stakeholders. This could include developing and broadly disseminating best practices in effective application and communication strategies that encourage enrollees and patients to self-report their demographic information, including developing accessible multilanguage messaging on how these data will be protected and used. Several key informants also suggested that application assisters, brokers, and navigators, as well as staff assisting patients in health care settings, should receive education and periodic training on culturally effective and bias-free practices that support effective data collection. These strategies and practices should be developed and implemented with community input to effectively identify and address the barriers and reservations of health care consumers and providers in self-reporting demographic data.
- Allocating adequate funding to support the infrastructure and technical assistance for effective data collection.

Standardizing and aligning data to support usability. The most frequently cited recommendation for federal policymakers to minimize the data collection burden and strengthen the usability of race and ethnicity data was to improve data use—not just within a single program but across different health care and social services programs and geographies. Strategies suggested by key informants included:

- **Developing and implementing clear and consistent data standards** on race and ethnicity categories and other demographic and socioeconomic characteristics in health care, public health, and social service sectors, perhaps building on the updated guidance on data standards recently proposed by OMB.

- **Aligning existing data sources and facilitating efficient and secure exchange of information**. This could include federal action to review and amend data privacy laws such as the Health Information Portability and Accountability Act (HIPAA), the Family Educational Rights and Privacy Act (FERPA), and others. The federal government could also regulate EHR records vendors more effectively to enforce greater standardization and interoperability of different platforms.

Implementing accountability, incentives, and consequences to support the use of data to reduce health disparities. Finally, key informants made the following recommendations for programs and policies and federal and state policymakers to promote greater use of stratified demographic data not only to measure disparities but to develop interventions to reduce disparities. These include:

- **Encouraging health care entities to embed health equity in their culture and operations**, such as the above-mentioned NCQA health equity accreditation or the CMS Hospital Commitment to Health Equity measure. [23]
- **Continuing to develop appropriate accountability mechanisms** through public reporting and incentives and/or consequences tied to health equity measures (ensuring that organizations make sustainable progress on reducing health disparities without diminishing access to and quality of care or excluding people with high needs from insurance and patient rosters).
- **Promoting evidence building by providing technical assistance and allocating financial resources for evaluation of interventions** designed to reduce health disparities.
- **Requiring that patients and communities are meaningfully involved** in designing, implementing, and evaluating health equity interventions (Kader and Smith 2021).

INSTITUTIONAL POLICIES AND PRACTICES

Outside the federal and state policy environment, key informants in our study identified several internal factors that can support an organization's ability and capacity to prioritize and invest in the collection and analysis of demographic data to identify and reduce health disparities. These factors include (1) securing and cultivating leadership support, (2) institutionalizing commitment to health equity within an organization, and (3) maintaining focus on the end goal when facing obstacles. Several informants reported sharing information and learning with other entities in their field, suggesting the need or opportunity for broader collaboration and learning networks within the health care sector on collecting and leveraging data in health equity efforts.

Securing and cultivating leadership support. Many key informants noted strong internal leadership was important for both driving the focus on equity within an organization and for securing adequate resources for data and other efforts to execute on the health equity vision. Informants further observed that advocacy from within and outside institutions often plays a key role in educating and persuading leaders to commit to health equity. For example, several state legislative efforts to collect and standardize race and ethnicity data—including in Connecticut, Minnesota, and Oregon—were reportedly driven by safety net health care providers and consumer advocates.[24] Others described internal advocacy efforts to cultivate leadership buy-in and support for data collection and analysis, including by presenting existing evidence on health disparities and developing an effective argument for how better race and ethnicity data can help both identify and reduce disparities. Several informants reported that the COVID-19 pandemic and racial justice movement increased the understanding of disparities among leaders, particularly those who may have been in denial or oblivious to disparities in the past. However, many also acknowledged that cultivating leadership support is an ongoing education process because of turnover in leadership positions and frequent changes in an organization's priorities.

Institutionalizing commitment to health equity within an organization. Because interest in addressing health disparities may wane or leadership and staff commitment may change over time, a few key informants noted the importance of institutionalizing commitment to health equity within an organization, including in its mission, goals, policies, operations, and culture. One informant characterized this as a process-based and broad effort that is not dependent on individuals but integrated into the core fabric of the organization. This is particularly important with respect to data collection and analysis which often represent a large-scale effort and investment of staff time and resources. As mentioned earlier, Sutter Health successfully expanded patient race and ethnicity data fields in its EHR upgrade and implemented staff training on data collection, so today collecting these data in patients' records is a standard procedure. Michigan Medicaid representatives described the longstanding prioritization of collecting and monitoring data on disparities by race/ethnicity that allowed the state to make investments in underlying infrastructure including data systems and workforce. Another informant pointed out that programs such as NCQA health equity accreditation may support health systems and health plans in institutionalizing health equity work.[25]

> *"[Lack of data on race and ethnicity] creates this 'data paralysis' … in many organizations where … [people say] 'I just can't trust [the data], so, I'm just not going to do anything related to health equity moving forward. [But instead let's say,] 'Let's start somewhere [even though] we know it's not complete.'… I also like to remind people that we also have qualitative data as well. [And we can still try] going out and building and continuing relationships with communities. Because that can also be very insightful … [While some people are] just focusing on the data, … [that] removes them [from] having to talk to their communities and build those relationships."*
>
> *—Study informant*

Maintaining focus on the end goal can facilitate progress despite hurdles. We heard repeatedly that organizations must be willing not only to collect but also to use data to inform decisions and develop and implement interventions to reduce disparities. Keeping this end goal in mind can be important, particularly when starting or improving race and ethnicity data collection, and analysis may seem overwhelming or the return on investment is unclear. A common sentiment was that the lack of data should not be an excuse for not prioritizing and committing to reducing health disparities. This inaction, in turn, stalls progress in building evidence on what health equity interventions are effective. As one informant put it, "data paralysis" can be an unnecessary hindrance to innovation in how organizations understand and address disparities. Another urged health organizations to not let the "perfect" be the enemy of the good, and yet another one cited Arthur Ashe's call to start with where you are and use what you have. One informant shared that addressing disparities may not necessarily involve huge efforts, expensive new infrastructure, or fancy analytics:

> I hate to simplify it in this way. But … if today, we asked providers for 20 fields of data and tomorrow we need 22, that shouldn't require a ton to investment to collect and do something with it … I think any organization can obtain these [race and ethnicity] data and can use them. [Organizations] can take that information and learn from that information and then enable their organization to take action.

Several key informants urged decisionmakers across a range of sectors to build on the ongoing momentum to advance health equity, seizing the current moment of deep interest in health equity to improve not only the collection but also the use of race and ethnicity data to inform public health and clinical policies and practices that could reduce health inequities.

Conclusion

The pandemic and ensuing social unrest led to a significant increase in efforts to address health inequities, including by collecting and analyzing individual race and ethnicity data in the health care sector. This study found that despite some progress in improving data quality, many of the challenges to race and ethnicity data collection identified in *Unequal Treatment* persist. Data collection efforts remain unsystematic. The lack of consistent and inclusive data standards has left some organizations unclear as to how they should proceed. Finally, a lack of financial and educational resources and federal requirements have contributed to delayed collection and reporting efforts. Given the current state of data collection, it is not surprising that efforts to use race and ethnicity data to develop and evaluate health equity interventions are few and far between.

While many of these findings seem less than optimistic, key informants highlighted that the health care sector needs to build on the current window of opportunity when interest and support for advancing health equity are strong, despite some pushback.[26] Informants urged health care stakeholders not only to sustain efforts to improve patient demographic data collection but also to aggressively pursue data analysis and application to develop and test effective health equity interventions and reduce racial and ethnic health disparities. Efforts also need to focus on strengthening data collection of the social drivers of health and people's experiences with provided care to ensure that 20 years from now, we will not only have complete and accurate data, but we will have used it to eliminate health disparities.

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