



RESEARCH REPORT

# Collection of Race and Ethnicity Data for Use by Health Plans to Advance Health Equity

## Opportunities, Barriers, and Solutions

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# Contents

<b>Acknowledgments</b>	<b>iv</b>
<b>Executive Summary</b>	<b>v</b>
<b>Collection of Race and Ethnicity Data for Use by Health Plans to Advance Health Equity</b>	<b>1</b>
Introduction	1
What Are the Opportunities for Better Race and Ethnicity Data Collection to Advance Health Equity?	4
How Health Plans Can Use Race and Ethnicity Data to Advance Health Equity	5
What Solutions Could Reduce Existing Barriers to Race and Ethnicity Data Collection?	9
1. Build Consumer Trust and Enhance Community Engagement	9
2. Reduce Actual and Perceived Legal Concerns and Uncertainty	13
3. Update and Standardize Self-Reported Race and Ethnicity Data Collection Practices and Build Consensus on Who Should Collect and Share Data	16
4. Prioritize Organizational Capacity and Sufficient Resources to Collect, Analyze, Share, and Use Race and Ethnicity Data	22
What Should Happen Now to Jumpstart Action?	23
1. Multisector Stakeholders Should Begin Working Together Immediately (but It Will Take Time to Achieve Needed Results)	23
2. Individual Reporting Should Be Voluntary and Organizations Collecting Data Should be Adequately Resourced	24
3. Government Agencies, Health Plans, Employers, and Individuals Should Work Together to Develop Guardrails That Help Ensure Data Security and Patient Privacy and Prevent Harms to Historically Marginalized Groups	24
Conclusion	25
Notes	27
<b>Appendix. Potential Legal Barriers to the Collection, Storage, Use, and Disclosure of Participant Race, Ethnicity, and Language Data by Group Health Plans and Group Health Insurance Issuers</b>	<b>28</b>
<b>References</b>	<b>35</b>
<b>About the Authors</b>	<b>37</b>
<b>Statement of Independence</b>	<b>38</b>

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# Executive Summary

Evidence of disparate health outcomes by race and ethnicity (R/E), exposed most recently by the COVID-19 crisis, has spurred momentum to reduce health inequities and highlighted health plans' and other organizations' need for access to high-quality R/E data as a step toward advancing health equity (AHA 2020; Grantmakers In Health 2021; McAvey and Reginal 2021; National Commission to Transform Public Health Data Systems et al. 2021). Despite being acknowledged as a limitation for decades, R/E data remain incomplete and inconsistent and are not able to be easily shared across different entities in the health care sector, making it difficult to identify and track health inequities and to evaluate efforts to reduce them.

This report is based on a literature review on the status of health plans' R/E data collection and perceived and actual barriers to collecting these data, more than 50 expert interviews, informal surveys conducted by the Deloitte Health Equity Institute and the American Benefits Council, and the Summit on Race and Ethnicity Data Collection for Health Equity that included 27 stakeholders representing multiple sectors including health insurance plans; technology firms; health care providers; employers; community-based organizations; foundations; and advocacy, public health, and research organizations. We assessed stakeholders' suggestions for how to improve the collection of R/E data for use by health plans and identified high-priority next steps. This report considers the following questions:

- What are the **opportunities** for better R/E data collection to advance health equity?
  - » **Health plans (including employer-sponsored group health plans) are uniquely positioned to use R/E data to advance health equity.** Interviewees and summit participants described various initiatives that health plans could drive at the plan level, including monitoring patterns of access to and use of health care services, health care quality, patient safety, consumer perceptions of care, and health outcomes; more effectively directing health care resources; creating incentives for providers to reduce disparities; publicly reporting on providers' and plans' progress in addressing inequities; and testing algorithms and interventions to avoid bias.
  - » **Expanded use of R/E data could be valuable for numerous constituent groups.** For example, patients could benefit from improved interactions with the health care system and initiatives to address health disparities. Health care providers could gain insights into equitable delivery of health care services. Employers could benefit by making more informed decisions concerning the health plans under which their employees are covered

and the providers from whom employees receive services and could ensure benefits are addressing the needs of underserved employees.

- What **solutions** could reduce existing **barriers** to R/E data collection?
  - » **Build consumer trust and enhance community engagement.** Summit participants identified consumer mistrust as a key barrier. They noted that historically marginalized people may worry that providing R/E data will create further harms in the form of possible discrimination, biological explanations of or blame for inequities, and inappropriate or differential treatment. They recommended various strategies to build and maintain trust with individuals throughout the health ecosystem that could encourage self-reporting R/E data, many of which could be designed to address specific concerns, including past and present harms by the health care sector and fears about data misuse. Strategies could include incorporating community engagement and trusted community partners in efforts to improve data collection, communicating transparently about the reasons for collecting R/E data, and developing with the community guardrails to ensure data security and patient privacy. Participants also recognized that making the health care system more trustworthy and gaining trustworthiness are processes that will take time and require community engagement, accountability, and long-term commitments, including showing the value of data collection in reducing inequities.
  - » **Reduce legal concerns and uncertainty.** A legal analysis conducted as part of this project found no state and federal laws that bar employers, third-party administrators, and group health plans from collecting and sharing R/E data for a permitted purpose, such as reducing health disparities. However, employers are often hesitant to do so because of a lack of clarity around legality and permissibility. Summit participants suggested stronger signals from federal and state governments clarifying the legality of collecting and sharing R/E data could be helpful.
  - » **Update and standardize self-reported R/E data collection practices and build consensus on the roles of plans, providers, employers, and the government in collecting and sharing data.** Stakeholders maintained that outdated, inconsistent standards limit progress in data collection and use. For instance, current R/E response categories limit the extent to which people see their identities reflected when asked about their R/E, which may reduce their interest in responding. Stakeholders also offered perspectives on the role of providers and health systems, employers, state and federal agencies, and health plans in the collection and storage of such data. They contended that community input is needed for developing more inclusive standards for self-reported, voluntary R/E identification that reflects

community identities; moreover, such transformation should include investments in updated, interoperable data systems.

- » **Prioritize organizational capacity and provide sufficient resources to collect, analyze, share, and use R/E data.** Participants suggested that better communicating the value of improved R/E data collection and a showing the feasibility and value of data collection in reducing disparities could help encourage cultural shifts within organizations toward data collection, but adequate resources for technological tools and training for frontline workers would be essential.
- What should happen now to **jumpstart action**?
  - » Multisector stakeholders should begin working together immediately (but it will take time to achieve needed results).
  - » Individual reporting must remain voluntary, and organizations collecting data should be adequately resourced.
  - » Government agencies, health plans, employers, and individuals should work together to develop guardrails that ensure data security and patient privacy and prevent harms to historically marginalized groups.

In addition, the above actions could ideally include health plan engagement with communities, distribution of sufficient resources for staffing and necessary technical updates, and multisector advocacy to provide recommendations on updated federal standards and clear guidance. Input from summit participants and interviewees also helped guide the creation of a resource found in an appendix to this report that includes a detailed analysis of whether any federal and state laws may stand as legal barriers to the collection, storage, use, or disclosure of R/E data by private parties. Stakeholders also emphasized that R/E are just one element of long-standing structural inequity and that additional factors such as sex, sexual orientation and gender identity, immigration status, language, and disability status, as well as intersections of those identities, will also be important to assess. Moreover, improvements in R/E data collection should be accompanied by changes specifically designed to eliminate racial and ethnic disparities in health care experiences and outcomes.

Though improved data collection alone will not solve long-standing racial and ethnic health disparities, summit participants and other key stakeholders viewed it as a critical step. As one interviewee stated, the absence of data hides injustices in systems of care. Many stakeholders expressed the urgency of this moment and the critical need for simultaneous, multisector action, supported by sufficient resources, that not only identifies disparities but is followed by interventions to close equity gaps.



# Collection of Race and Ethnicity Data for Use by Health Plans to Advance Health Equity

## Introduction

Disparities in health care treatment and outcomes by race and ethnicity (R/E) have been documented for decades and were featured prominently in the Institute of Medicine's *Unequal Treatment* report (IOM 2003). The COVID-19 pandemic drew broader attention to structural racial and ethnic inequities in the health care system and the enormous human, financial, and social tolls of not addressing them (Chowkwanyun and Reed 2020; LaVeist, Gaskin, and Richard 2011; Ndugga and Artiga 2021; Waidmann 2009).

Public health experts have noted that R/E data are needed to identify health inequities and to design meaningful strategies to advance equitable health outcomes (Grantmakers In Health 2021; McAvey and Reginal 2021; National Commission to Transform Public Health Data Systems et. al. 2021). However, studies assert that data gaps, limited data collection requirements at the federal level, and restrictions (real and perceived) on what questions group health plans, insurers, and others can ask of enrollees impede such efforts (HHS 2011).<sup>1</sup>

Currently, data standards vary dramatically across types of health insurance, leading to wide variation in the completeness of R/E data in public versus private coverage and across health plans' lines of business (Grantmakers In Health 2021). Some investigations show R/E data for fee-for-service Medicare enrollees are relatively complete because of the use of Social Security Administration records, but gaps and limitations exist (e.g., poor data quality due to limited R/E categories), and changes to recordkeeping mean data will become less available as new enrollees age into eligibility (CMS 2017; Grantmakers In Health 2021; Martin 2016; Office of the Inspector General 2022). State Medicaid applications ask enrollees to report their R/E, but response standards vary across and within states. Additionally, responses are optional under federal law because they are not used for determining eligibility, leading to low rates of completeness and low data quality in many states (MACPAC 2022). Marketplace applications also request, but do not require, R/E reporting, and studies find high rates of missing data and variation in completeness across states.<sup>2</sup> The Centers for Medicare & Medicaid Services has used data imputation, additional data collection, and other means to increase the

availability of R/E data, and highlighted the need for more complete data (CMS 2022; Haas et al. 2019). Other public systems, such as the Veterans Health Administration, Indian Health Service, and federally qualified health centers, collect R/E data, but the data are not always standardized or sharable with other systems (Grantmakers In Health 2021). Less is known about the extent of data collection for commercial coverage; R/E data may be collected by providers or in electronic health records or, for those with employer-based coverage, by employers, but these data are seldom shared across health systems or with health plans. For instance, one large payer has reported that just a quarter of its commercial population has complete R/E data, which were mainly collected via electronic medical records, labs, enrollment forms, and immunization registry data.

Moreover, when R/E data are collected, the use of relevant data standards varies, and certain federal standards may not reflect the diversity of the population for which they are used. The federal government's chief statistician recently announced plans to revise the R/E data standards used across federal programs.<sup>3</sup> Currently, the Office of Management and Budget's 1997 standards collect racial and ethnic identification separately and allow reporting of more than one race, but they provide only five minimum categories for race and two for ethnicity (Grantmakers In Health 2021). The Affordable Care Act's US Department of Health and Human Services 2011 standards provide more detailed response options, but these standards still lack the granularity needed to identify people in less common racial groups, such as individual American Indian/Alaska Native tribes. Because these standards condense diverse racial and ethnic groups into broad categories, using the minimum federal standards can result in limitations in the use of the data for disaggregation. Moreover, many consider self-identification to be the "gold standard" (Grantmakers In Health 2021; Shapiro et al. 2021). But data such as those found in medical records may be recorded by a provider based on appearance, and, when data are missing, imputation may be used to assign R/E based on other characteristics, which some studies find to be inaccurate and to introduce bias (Brown et al. 2021; Fremont et al. 2016).

Though a lack of complete, accurate, consistent, and self-reported data with sufficient granularity has long been acknowledged as a problem, to date little progress has been made in improving data collection. This highlights the urgency of needed action to confront the main barriers to collecting and sharing complete R/E data, which could equip health plans and other stakeholders with the tools to promote equitable health outcomes.

For this project, the Urban Institute, the American Benefits Council, and Deloitte's Health Equity Institute assessed opportunities for improved R/E data collection, barriers to complete and accurate data collection, and solutions for achieving comprehensive availability of self-identified R/E data for use by health plans and other stakeholders to advance health equity. In the spring of 2022, we conducted a

literature review of R/E data collection by health plans and perceived and actual barriers to collecting these data (Alvarez Caraveo et al. 2022), conducted more than 50 expert interviews using a standardized interview guide, administered informal surveys (conducted by the Deloitte Health Equity Institute and the American Benefits Council), and held the virtual Summit on Race and Ethnicity Data Collection for Health Equity. The summit included 27 stakeholders representing health insurance plans; technology firms; health care providers; employers; community-based organizations; foundations; and advocacy, public health, and research organizations. Summit attendees included the following:

- Khadijah Ameen, BLKHLTH
- Missy Danforth, The Leapfrog Group
- Mario De La Rosa, Florida International University
- Brian Delphey, Navistar Inc.
- Nicole Evans, National Academy for State Health Policy
- Deanna Fulp, Blue Cross Blue Shield of Massachusetts
- Darrell M. Gray II, Elevance Health
- Viannella Halsall, American Academy of Family Physicians
- Virginia Hedrick, California Consortium for Urban Indian Health
- Ivor Horn, Google
- Julia Iyasere, NewYork-Presbyterian Hospital
- Valarie Blue Bird Jernigan, Oklahoma State University
- Shyloe Jones, Families USA
- Diana Lemos, American Medical Association
- James Lillard, Morehouse School of Medicine
- Elizabeth Lukanen, State Health Access Data Assistance Center
- Enrique Martinez-Vidal, Association for Community Affiliated Plans
- Ryan Mattiza, AT&T
- Ernest Moy, Veterans Health Administration
- Debbie Peikes, Humana

- Alonzo Plough, Robert Wood Johnson Foundation
- Susan Rawlings Molina, GroundGame Health
- Sarah Shih, National Committee for Quality Assurance
- Erica Spears, Louisiana Public Health Institute
- Pascale Thomas, The Walt Disney Company

This report presents key themes and insights from the analysis, interviews, and summit that address three key questions:

- What are the **opportunities** for better R/E data collection to advance health equity?
- What **solutions** could reduce existing **barriers** to R/E data collection?
- What needs to **happen now** to jumpstart action?

## What Are the Opportunities for Better Race and Ethnicity Data Collection to Advance Health Equity?

Complete and accurate data are essential for tracking how health outcomes and access to high-quality care differ for different racial and ethnic groups and how such differences vary geographically and over time. This information may be used as part of initiatives to

- hold health plans, health care providers, and integrated health systems accountable for delivering high-quality care for everyone;
- uncover standards of care that may vary across diverse R/E populations; and
- guide the design of tailored interventions to promote equitable health care delivery while enabling evaluations of how different health care treatment approaches affect different groups.

Many study participants indicated that a lack of understanding and communication of the value of improved R/E data collection has been a barrier to progress. To help address this barrier, in the following section we describe our findings on the value that improved data collection holds for constituent groups and the potential risks associated with some uses of such data.

## How Health Plans Can Use Race and Ethnicity Data to Advance Health Equity

Stakeholders asserted that health plans are well positioned to normalize R/E data collection, make productive use of the data, and lead important efforts to improve health equity. They also noted that plans (and payers more broadly, including Medicare, Medicaid, health insurance Marketplaces, and administrators of employer-sponsored health plans) often have the broadest and most comprehensive view of a person's health care utilization. Even the most integrated health care system using electronic health records may lack some information about a patient's utilization, such as utilization of prescription drugs and services patients obtain outside the system. This gives health plans a unique opportunity to identify and address disparities.

Initiatives to improve health equity may operate at a population or individual level. The types of initiatives that health plans could drive at the population (or group aggregate) level, found in our literature review and discussions with interviewees and summit participants, include the following:

- **Internal monitoring of health equity patterns and trends.** Health plans can use member R/E and health data to compute a range of quality and equity measures that capture disparities in health care access, clinical outcomes, and consumer engagement and satisfaction.
  - » Plans can track progress in improving health equity by examining changes in outcome measures by group and changes in equity measures over time.
  - » An analysis of geographic patterns in outcome measures across and within racial and ethnic groups can identify areas where health care needs and/or structural barriers to care are most significant and where members need additional support accessing quality care. For example, on finding a high prevalence of diabetes among American Indian/Alaska Native people in a group of counties, one participant recounted their organization discovering that access to diabetes care and medication adherence were challenges for this group. This led the organization to engage community representatives and develop a targeted medication distribution program.
  - » R/E data could also be used to monitor the use of telehealth in different communities and to develop interventions to help people use telehealth where uptake is low, such as offering technical assistance and training at community centers (Russell et al. 2022).
- **Public reporting of providers' health equity outcomes.** For providers that serve sufficient numbers of a plan's members, plans can produce provider report cards that show how well providers perform on health equity. The report cards could report quality measures separately by group and illustrate differences across groups (possibly including statistical adjustment for

the effects of age, sex and gender, and health conditions, as the Institute of Medicine and others have recommended for measuring health care disparities; IOM 2003; Lê Cook, McGuire, and Zuvekas 2009). Members could use this information when selecting providers. Plans could then account for providers' equity performances when designing provider networks or value-based contracting programs. To make the most of this opportunity, competing plans within a market could consider pooling their provider-level data to create more complete, representative, and statistically reliable provider scores.

- **Identifying where additional health care resources are needed.** Based on their monitoring efforts, plans could implement tailored interventions aimed at improving equity and overall care quality. Plans could adjust their provider networks to include providers best able to meet a community's health care needs. Also, if some communities are found to be underrepresented in care-management programs, plans could add further care-management resources tailored to that community (e.g., employing care or case managers who are from the community or have cultural competency training). An interviewee described combining a "hotspotting" data analysis with the design of community interventions: for example, if a larger share of women of a particular racial or ethnic group in a certain zip code give birth to infants with low birth weight relative to other women in the area, health plans could implement prenatal health interventions in the region specifically tailored to such women.
- **Public reporting of plan-level equity outcomes.** For the benefit of health care consumers, plans may further use R/E data to help produce equity report cards on themselves. Prospective members and employer sponsors of health plans could then use this information in their health plan choices, with the idea that plans would seek competitive advantage by working to improve health care equity and quality among their members.
  - » Plans may choose to self-report this information. But for such an initiative to work, plans would likely need to submit plan-level data that meet specified standards to a governing body that would then compile them with submissions from other plans and publish the scores for all participating plans in one place so consumers can compare plans.<sup>4</sup>
  - » Plan equity measures are needed alongside (or as part of) overall plan quality measures because even among plans with high quality scores, considerable R/E disparities may persist that require focused improvement efforts. For example, in a recent study of Medicare Advantage plan quality measures (star ratings), higher-performing plans had *larger* racial and ethnic disparities in care (Meyers et al. 2021).

- **Creating incentives for health care providers to improve health equity.** Through the payment arrangements they make with providers for furnishing health care services to members, commercial health plans can pursue value-based payment models that tie payments to health equity and quality. An emerging example of this approach as applied to Medicare is the Accountable Care Organization Realizing Equity, Access, and Community Health Model.<sup>5</sup>
- **Allowing research to guide the design of health equity interventions and evaluations of the effectiveness of such interventions.** With health data on large numbers of individuals linked to accurate and complete R/E data across geographies and over time, health plans could be positioned to conduct both publishable and proprietary research that evaluates what interventions are effective in improving both health equity and health care quality for different racial and ethnic groups.
- **Detecting potential bias in algorithms that identify particular treatments or interventions for individual patients.** Treatment and other decisionmaking algorithms, increasingly developed using machine learning and artificial intelligence, may be used by health plans and systems in various ways, including for identifying members predicted to be at high risk for poor outcomes to connect them to specific medical interventions. Even though R/E are not used as an input to such algorithms (both for ethical reasons and to avoid perpetuating disparities in care), the outputs determining risk levels may nonetheless show bias (Norori et al. 2021). High-quality R/E data can be used to test such algorithms for any inadvertent bias toward or against specific groups so problems can be addressed before algorithms are deployed.

Very few participants described initiatives that directly use R/E data and operate at the individual level, whereby care decisions are based on one's racial or ethnic identity. Many participants stressed, instead, that interventions should address the root causes of health inequities. These include food availability and diets, access to transportation, housing, air quality and other environmental exposures, and financial security. As one participant put it, "There is no intervention for [race or ethnicity]." Another explained that "the value proposition for collecting R/E data is not understood at an individual level in the same way that it is at the population level....at an individual level, it is less obvious how a provider or patient benefits from the exchange of R/E information."

One participant offered this scenario: if R/E data are accurate at an individual level, the data can inform personalized communication and provide context and support for plan members. Further, if a case manager knows a member's R/E before contacting the member, the case manager could learn to connect with the member better. But the participant also noted the risk that a case manager (or provider) could make incorrect assumptions about a member using this information. This example

highlights the importance of identifying what type of individual data should or should not be employed and of carefully scrutinizing data use to identify possible unintended consequences.

Many participants described value in linking individual-level R/E data to publicly available data on social factors that could affect health outcomes (such as access to transportation and environmental exposures measured at the zip code level). One stakeholder described the potential for linking individual R/E data, publicly available data (like the Social Vulnerability Index data), and claims data to examine social risk factors within an employer's or provider's population or examining health gaps (e.g., lack of adherence to preventive care or medications) to make preliminary inferences about the role of local systemic issues. But more work would be needed to understand how linked data could be used, what applications would be considered appropriate or inappropriate, and which types of well-intentioned individual-level uses of R/E data by health plans (linked or not) are acceptable. Because the most significant potential positive impact of collecting R/E data is improvement in the care rendered to individuals, investment in studies that evaluate the best ways to measure R/E and the effectiveness of interventions that use these data is needed.

Another potential use of R/E data frequently mentioned in our discussions is for achieving greater racial and ethnic alignment between patients and health care providers and staff at providers' offices. At the population level, this could involve plans building provider networks that reflect the member population. At an individual level, with R/E data on members and providers, case managers could work to match members with providers of the same R/E if the member desires. One participant explained that patients often care about whether their provider understands their culture, so having plans understand their members' cultural identities could enhance the patient experience.

Because the opportunities of improving the collection and use of R/E data are focused on delivering high-quality care for all member groups, the potential benefits of these improvements clearly accrue to consumers. But these efforts have significant value for other constituent groups as well. Health care providers could benefit from improved understanding of what health care practices and interventions are most effective for their patients. Employers could benefit from ensuring a healthy and productive workforce derived from more visibility into whether employees' health care needs are being met and which employees' needs are most likely to go unmet. Employers could also have better information with which they could hold health plans and third-party administrators accountable for meeting all employees' health needs equitably and with high quality. Health plans could benefit from improved member experiences, better clinical outcomes, and improved capacity to reward providers that deliver high-quality care and improve outcomes for all members.

# What Solutions Could Reduce Existing Barriers to Race and Ethnicity Data Collection?

Stakeholders we interviewed and who attended the summit proposed several ways to reduce existing barriers to collecting and sharing R/E data, including building consumer trust and enhancing community engagement; reducing actual and perceived legal concerns and uncertainty about sharing R/E data between health plans, employers, and providers; updating and standardizing self-reported R/E data collection practices and deciding who should collect and share such data; and prioritizing organizational capacity and sufficient resources to collect, analyze, share, and use R/E data.

## 1. Build Consumer Trust and Enhance Community Engagement

Summit participants and interviewees described several barriers to more complete R/E data collection and potential solutions. First, given participants' widespread agreement that the gold standard for R/E data is individual self-reporting, health plan members should be comfortable sharing information about themselves. Otherwise, other improvements to R/E data collection will be moot. Stakeholders we interviewed and summit participants noted the varied reasons people may not be willing to share their R/E, including the following:

- Historic and present-day structural racism that operates throughout the health care system in the form of discrimination and unequal treatment creates a reluctance to provide R/E data among some groups of people.
- Even if a health plan is committed to health equity, members may not always see health plans as trusted entities.
- Some people do not see their identities accurately represented in the R/E choices available, so they do not respond to questions about their R/E. We heard concerns about this for several groups, including Middle Eastern and North African people; American Indians/Alaska Natives, who are often classified as “other race” and are not given the opportunity to identify their tribe; people who are multiracial; and Hispanic people who do not identify with provided racial categories.
- Members do not have a clear understanding of why R/E data are being collected and how they will be used. Summit participants noted that historically marginalized people worry that providing R/E data will create further harms in the form of discrimination, biological explanations of or blame for inequities, and inappropriate or differential treatment. Because of this, some people are unwilling to provide their R/E, especially when a person is unlikely to

benefit from doing so. As one participant noted, no clear individual upside to sharing data exists, and people may not want to share their personal information only for the greater good.

- More broadly, members worry about who will have access to their data, how their data will be protected, and what the guardrails are for the use of their data.
- Few participants mentioned how employees may feel about their employers sharing R/E data with health plans and plan administrators, but it likely raises the concerns mentioned previously about guardrails for using these data.

To better understand people's willingness to share and concerns about sharing R/E data, the Deloitte Health Equity Institute conducted a nonscientific online survey of US adults ages 18 and older (box 1). About 80 percent of respondents who completed the survey said they were willing to share their R/E data with their health plans. However, more than half of respondents had concerns about who their data would be shared with or sold to. Across different races and ethnicities, white respondents were the least likely to have these concerns and were the least likely to be concerned about being misdiagnosed, judged unfairly, or denied coverage. Though the research results come from a convenience sample of paid panel respondents and thus may not fully represent the entire US population, these findings indicate some potential sources of discomfort, particularly about data sharing, that would need to be addressed to build trust around data-sharing protocols. They also highlight the potential variation in comfort with data sharing by racial or ethnic group.

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#### BOX 1

##### **Individual Perspectives on Reporting Race and Ethnicity Data to Health Plans Illustrate Concerns about How Data Will Be Shared or Sold**

The Deloitte Health Equity Institute conducted an online survey of 3,327 US respondents ages 18 and older in April and May 2022 that inquired about respondents' willingness to share various types of data across different organizations and systems and concerns about sharing such data. Among the survey's findings are the following:

- Seventy-nine percent of people responding to the survey said they were comfortable sharing their R/E data with their insurance providers.
- However, 59 percent also cited concerns about sharing R/E data with their "healthcare provider, insurance company, and/or community-based health organization" due to discomfort about how the information would be shared with or sold to others without their consent.
- White respondents tended to feel less discomfort with sharing R/E data than Asian, Black, or Latino/a respondents across various sources of discomfort, including those related to a lack of

consent, concerns about misdiagnosis, unfair treatment, not understanding the reason for sharing such data, the potential for uncovered claims, and discrimination.

**Source:** Heather Nelson, "Trust, Inclusivity May Be Key to Richer Race/Ethnicity Data," *Health Forward* (blog), Deloitte, July 14, 2022, <https://www2.deloitte.com/us/en/blog/health-care-blog/2022/trust-inclusivity-may-be-key-to-richer-race-ethnicity-data.html>.

**Notes:** Results are drawn from a voluntary response convenience sample weighted to match the R/E distribution in the 2020 Census; nonprobability sampling strategies may still contain bias after weighting and may not be nationally representative. For instance, people who are more concerned about data privacy may be less likely to respond to an online survey, and people who do not use the internet and people who do not speak English are excluded.

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Summit participants recommended various strategies for building and maintaining trust with consumers throughout the health care system that could encourage self-reporting R/E data. Many of the strategies address specific sources of discomfort, including fears about data misuse identified in the above-mentioned survey. In general, participants thought that members need to trust that health plans will do no harm with R/E data and that plans should communicate to members the value of R/E data collection and the boundaries of how such data will be used. Participants also recognized that gaining trustworthiness is a process that will take time and require community engagement, accountability, and long-term commitments.

A summit participant shared that one health plan has been collecting voluntarily self-reported R/E data directly from its members for more than a year, and it has faced little concern from members or employers (and, in fact, has received positive, constructive feedback, for example, to include more granular R/E categories to choose from). Instructions on the web portal or online survey indicate the reason for data collection and promise confidentiality.<sup>6</sup>

Participants also indicated that discussions of trust should be reframed into changing *systems* rather than *individual attitudes*; for instance, one shared the following:

We talk about lack of trust as this thing related to the individual from an individual context. And really it is institutional trustworthiness, and lack of trustworthiness, that is a problem. And so as we talk about this measure, reframing it to think about, how do we reframe what institutions, what organizations have trustworthiness? And oftentimes there will be these limitations to an institution being able to be trustworthy because of long historical structural racism and bias within those systems. So then the question becomes, how do we get to...trustworthiness?

Multiple stakeholders talked about the importance of bringing members into the development of R/E categories to ensure people see themselves in the questions being asked, which could increase the likelihood that they will provide their information. Given variation in racial and ethnic groups across geographic areas, the ability to adapt the R/E questions to more granular categories that can be

combined into standardized groups can be important for making people feel included. This granularity can also make provider, plan, and public health efforts to advance health equity better able to focus interventions on the specific groups and communities they serve.

In addition, many summit participants shared that trusted community partners may be most effective at collecting R/E information from historically marginalized people. But it will be essential to inform people and communities about the reason for R/E data collection and to be transparent about how data will be used. As one participant stated, “For health plans or other academic or employer institutions to engage those who are most proximal to community members is going to be critically important for this to be successful.” Some of these trusted community partners may be organizations with whom health plans have relationships, such as federally qualified health centers and other safety net providers; community-based organizations that refer people to or provide assistance for health-related social needs such as food or housing; and organizations providing case management or care coordination. However, it is unclear how willing such organizations may be to play this role and how to efficiently share data between these organizations and health plans. Such connections may be especially important for racial and ethnic groups that include many people, such as undocumented immigrants, who may especially worry about the harmful consequences of sharing their information with less-well-known entities.

Even if health plans engage with community partners, whether they be federally qualified health centers, other providers, or community-based organizations, to elicit R/E data, several commitments from health plans would increase trust. These include being transparent about how the data would be used and involving community members in developing guardrails, paying community partners for their labor and engagement, sharing identified disparities back to the community, and engaging communities in developing solutions.

Some summit participants felt that sharing with the community the results of health plans’ analyses of health care experiences and outcomes by R/E could empower people to engage in advocacy for change; people could move “from powerlessness to power and from distrust to agency,” as one interviewee stated. They suggested that short- and long-term metrics for accountability be developed in conjunction with community partners, members, and patients and be committed to by health plans.

More generally, some summit participants advocated for collecting and sharing R/E data across multiple sources, such as providers, electronic medical records, federal and state governments, community-based organizations, employers, and health plans, and then combining the information for use by plans and other stakeholders. At the same time, participants had a clear consensus that members

should be able to control with whom their R/E data are shared, which will require clear consent agreements that are written in plain language and discussed with members, participants, and employees. Importantly, blanket consent agreements may lead some people to be reluctant to provide R/E data in these settings. Other respondents spoke about the challenges of asking for and talking about R/E (and the need for training health care and health system workers on how to have these conversations); they suggested that R/E data collection should rely on relationships and systems with which individuals have multiple contacts over time and that the challenges of such discussions could normalize over time. Finally, summit participants clearly agreed that reporting R/E data should be voluntary; as one participant noted, requiring data reporting can inhibit, rather than build, trust.

## 2. Reduce Actual and Perceived Legal Concerns and Uncertainty

Study participants identified other notable opportunities for data collection and sharing beyond building trust among individuals, but they also shared potential challenges. Many employers collect employees' R/E data (with their consent, often during onboarding) for specific internal purposes and reporting requirements under federal nondiscrimination laws.<sup>7</sup> Because about half of the US population has employer-based health insurance, employers are a potential source of information on many health plan enrollees' races and ethnicities (Grantmakers In Health 2021; National Research Council 2004). A legal analysis conducted as part of this project, provided in full in the appendix and summarized in box 2, did not identify state or federal laws that prohibit employers from collecting and sharing R/E data with group health plans, third-party administrators, or group health plan insurers for a permitted purpose, such as reducing health disparities.

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### BOX 2

#### Summary of Legal Analysis of Federal and State Laws on Race and Ethnicity Data Collection

Based on the legal analysis in the appendix, the federal landscape for R/E data collection and sharing is as follows:

- **No federal law was found that prohibits the collection, storage, use, or disclosure of R/E data** by group health insurance plans (whether insured or self-funded) for a permitted purpose.
- **No federal statute prohibits employers from sharing R/E data** for other purposes with group health plans, insurers, or third-party administrators.

The state-level landscape for R/E data collection and sharing is more varied:

- **For self-insured group health plans, state laws generally will not apply.**

- **For insured group health plans, state laws generally apply and could pose a legal barrier.**
  - » Some state insurance laws prohibit R/E data collection during enrollment, but **an analysis did not find laws prohibiting collection after enrollment**, and some laws, in fact, mandate R/E data collection.
  - » **No state privacy law was found that bars R/E data collection by group health plan insurers**, but some states may place additional restrictions on the use and disclosure of such data (because states are permitted to impose additional restrictions beyond those imposed by HIPAA, or the Health Insurance Portability and Accountability Act).

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And yet some employers expressed concerns about sharing R/E data with health plans or other entities because of the unclear legality and permissibility of doing so under current laws and existing employee data consent contracts; employers did not indicate they would share such data when employees provided them. An informal American Benefits Council survey validates the influence of perceptions of legal and regulatory barriers on employers' behaviors (box 3).

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### BOX 3

#### **Employers' Perspectives on Collecting and Sharing Race and Ethnicity Data Highlight the Importance of Perceived and Presumed Legal Barriers**

The American Benefits Council conducted a quick-turnaround, nonrepresentative survey of large employers across the country in April 2022 to assess current R/E data collection and sharing practices,<sup>a</sup> receiving responses from 44 unique organizations. Among the survey findings are the following:

- Twenty-six of the 44 organizations (59 percent) currently collect R/E data in their capacities as employers, in addition to collection required by the Equal Employment Opportunity Commission. Five of these organizations also collect R/E data in their capacities as self-insured health plans.
- Fifteen of the 22 employers that collect R/E data (68 percent) do not share the data with anyone. Among these employers, the most commonly cited reason for not sharing the data (by four employers) was "perceived/presumed legal barriers." In addition, 11 employers (73 percent) indicated that "understanding the health plan's intended use of this data" would be a prerequisite for sharing their data with plans.
- Among the 12 organizations that do not collect R/E data, the most commonly cited reasons were "perceived/presumed legal barriers" (six responses), "expected employee hesitancy/reluctance" (six), and "concerns about potential litigation" (five).

**Source:** “Quick Survey: Collection and Use of Employee Race and Ethnicity Data,” American Benefits Council, accessed June 17, 2022, <https://www.americanbenefitscouncil.org/pub/76DBABAB-1866-DAAC-99FB-E21FB5CDA4DE>.

**Note:** Organizations were not randomly selected; the American Benefits Council sent the survey to a large group of employers and asked for voluntary responses, and only those who responded are included.

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Stakeholders maintained that eliminating misconceptions about legal barriers is critical to encouraging more data sharing by employers. In addition, group health plans’ and group health insurance issuers’ uncertainty about whether laws exist that would prohibit collecting R/E data (especially at the state level, with respect to insurers) may affect the collection or use of R/E data. Specifically, some stakeholders explained that the absence of a law prohibiting such collection and sharing is not enough. Instead, they highlighted the need for clear directives specifying that collection and sharing are not just allowed for permitted purposes but encouraged; one participant mentioned a desire for “concrete, factual references” to cite. The legal analysis in the appendix serves as such evidence. But summit participants also identified the need for clarification from the federal government, such as guidance from appropriate federal agencies, describing the legality and permissibility of R/E data collection and sharing. This guidance could clarify the preemption of state laws and specify protections for how data will be used, confidentiality safeguards, guidance on what is and is not allowed, and reinforcement that self-reporting is voluntary. Summit participants encouraged the formation of a multistakeholder coalition to push for such action, which could then come from appropriate federal agencies. Relevant agencies might include the Equal Employment Opportunity Commission, the US Department of the Treasury, the US Department of Health and Human Services, the US Department of Labor, or the Office of Civil Rights.

But even with such legal clarity, additional barriers, such as hesitancy due to liability and accountability questions (e.g., if an analysis were to reveal inadvertent disparities in benefits provisions for certain groups) and employee concerns about potential privacy and data breaches, may remain. More action will likely be needed to encourage data sharing between employers and health plans, as discussed below. Moreover, a broader focus on the need for data sharing could also be critical; as one participant stated, “If [clarifying guidance] seems like it’s a legal document, then it becomes a legal discussion when, really, it’s a health care discussion and an inequity discussion.”

### 3. Update and Standardize Self-Reported Race and Ethnicity Data Collection Practices and Build Consensus on Who Should Collect and Share Data

Summit participants and interviewees also described an urgent need for revised, consistent data collection standards for representativeness and comparability. In particular, a lack of revised guidance can keep forward-thinking states, providers, and others from improving data collection because they may be hesitant to invest in upgrading infrastructure when standards may change and then require further investment. Also, if current standards do not meet the local needs of states, providers, and others, they may customize their own standards, which could limit the ability to share and compare standardized data. Multiple stakeholders raised these concerns, including representatives of state Medicaid agencies and commercial insurers, many of whom insure people in both the public (Medicaid, Medicare, and the Marketplace) and employer (self-insured and insured group coverage) markets.

Stakeholders emphasized the need for federal guidance and leadership in setting standards, which would ideally be coordinated across and within federal agencies and be somewhat permanent (i.e., over changing administrations) yet adaptable when necessary. Public-private partnerships can have an important role in developing new standards; this could include geographically and racially diverse community input to define the list of R/E options consumers can select from so that many people could see their identities reflected. One participant described community input as “pivotal” not only in the development but in the implementation of these standards.

For government or private organizations considering new standards, stakeholders suggested the following :<sup>8</sup>

- Though participants mentioned the wide use of imputed R/E data, the accuracy of such data is limited and imputation is not preferred; they indicated that data should be self-reported when possible (i.e., if data are collected in a provider’s office, they should be provided by the patient, not recorded by intake staff).
- Response options should include multiple categories with instructions to “select all that apply,” perhaps with sequencing for preferred identities.
- Response options should be disaggregated for smaller subgroups, such as Middle Eastern and North African people, Native Hawaiians/Pacific Islanders, and American Indian/Alaska Native people, but with consistent roll-up to standards.
  - » Multiple stakeholders suggested using online forms with granular drop-down options that reflect the local community.

- Standards should be consistent across states and organizations but be varied in detail.
- Respondents should have an option such as “prefer not to disclose.”

Opinions on one standard—whether to ask about race and ethnicity separately or through a combined R/E question—are varied (Mathews et al. 2017). If race and ethnicity questions are separate, many people maintained that ethnicity could be listed first so Hispanic/Latino members see their identity represented, or Hispanic/Latino members could be given the option to not choose a race. Moreover, how to prioritize identities for those who report multiple races and/or ethnicities and those whose identities may be reported differently in different settings or over time is unclear; for example, identities could be prioritized based on the group a person most identifies with or by how a person feels they are seen by others (their “street race”<sup>9</sup>), on which basis they may experience unequal treatment. Leading practices should be better understood before being incorporated into federal standards.

Participants also highlighted a need for multisector alignment on *who* should collect and share data, sharing pros and cons for providers, employers, governments, and plans (table 1). Further cross-sector work will likely be needed to identify which of these entities could collect data to be shared with other sectors, perhaps building on which systems are most trusted, while keeping in mind what one stakeholder shared: that patients do not necessarily view entities within the health care system as more or less trustworthy than others but instead lack trust in the entire medical system. Though data will likely need to be collected and shared across sectors to ensure completeness and accuracy, informed patient consent to data sharing will be essential to establishing trustworthiness.

Regardless of which sectors are ideal collectors of data for sharing with other entities, stakeholders said consistent standards alone are insufficient. They pointed to logistical questions about

- the interoperability, or lack thereof, across fragmented markets and the need for technological transformations (and clarity on how such transformations will be funded);
- how data should carry over across systems to reduce redundancy in collection for the individual and to avoid repeated asks for people who do not wish to share;
- how to indicate (1) whether data are self-reported or self-identified or recorded by someone else (e.g., through an electronic medical record that is then shared with a plan or employer), (2) when data were collected (to note which response was provided most recently for people whose self-identities may change) and by what source (because data sources may have different sources of bias), and (3) what questions and response options were used;

- how to identify responses that best match a patient’s self-identity in cases where data sources indicate different responses;
- standards for imputation when needed;
- standards for an analytics framework for (1) how to report disparities in a granular and nuanced way for people reporting multiple identities, (2) how to draw comparisons across R/E categories, and (3) how to aggregate R/E categories; and
- best practices for making data collection user friendly and inviting.

TABLE 1

**Who Should Collect Race and Ethnicity Data for Use by Health Plans?**

*Considerations for operationalizing the collection, storage, and sharing of self-reported data*

	Opportunities	Challenges	What could help?
<b>Health care providers, clinics, hospitals, and health systems</b>	<ul style="list-style-type: none"> <li>■ Collection could build patient connection with providers, show providers' interest in meeting patients' needs, generate conversations about racial identity and mental/physical health, and further <b>build trust</b>.</li> <li>■ Intake and patient interview/discussion are <b>opportunities to collect R/E data</b>.</li> <li>■ Experience from Veterans Affairs and FQHCs shows <b>collecting R/E data through providers can work</b>; such data are often already being collected in some provider systems.</li> <li>■ Providers are <b>already trained for and used to uncomfortable conversations</b>.</li> <li>■ R/E and cultural information could <b>inform individual care decisions and help ensure those most at risk of poor outcomes get adequate care</b>.</li> <li>■ R/E data collection could encourage better discussions of R/E in <b>medical training and inform hiring decisions</b>.</li> <li>■ <b>Trust may be greater</b> for providers than for plans.</li> </ul>	<ul style="list-style-type: none"> <li>■ Categorization and data collection procedures <b>vary</b> across locations, systems, states, etc.</li> <li>■ Collection can feel <b>invasive</b> to patients, especially those with prior harmful interactions; patients may worry about being <b>mistreated or not prioritized</b>.</li> <li>■ Providers may feel <b>discomfort</b> or concern about unintended consequences of R/E data collection.</li> <li>■ Collection could add another element to workflow and <b>overburden less-resourced providers</b>, especially if mandates or penalties are instated.</li> <li>■ Use of <b>observed rather than self-reported</b> R/E data may be common.</li> <li>■ Collecting data in these settings <b>excludes</b> people who do not obtain medical care.</li> </ul>	<ul style="list-style-type: none"> <li>■ <b>Funding and reimbursement</b> would need to be provided, especially to underresourced providers.</li> <li>■ <b>Education and training</b> for staff are needed, including training on approaching with humility and cultural competency and a “script” with answers to likely questions.</li> <li>■ Data collection should be added to <b>workflow</b> (including adequate time and resources) and may require additional <b>technology</b> (such as tablets and kiosks for patients to complete R/E questions).</li> <li>■ <b>Standardization</b> in R/E categories is needed.</li> <li>■ <b>Technology and data systems</b>, interoperability, and reporting capacity must be improved.</li> <li>■ Providers must understand the <b>role of structural factors</b> such as race and ethnicity in health outcomes and the <b>importance of data collection</b> to advance health equity.</li> </ul>

	Opportunities	Challenges	What could help?
<b>Employers</b> (may overlap with health plans and/or administrative services providers)	<ul style="list-style-type: none"> <li>▪ <b>R/E is already collected</b> for reporting to EEOC or DE&amp;I initiatives and could be shared with health plans, too.</li> <li>▪ <b>Some employers already share</b> EEO-1 Reports publicly.</li> <li>▪ Employers have vested <b>interest in workforce demographics and showing commitment to DE&amp;I</b>; opportunity exists to foster inclusive workplaces and improve health care for all employees.</li> <li>▪ Employers have capacity to <b>require plans to share disaggregated outcomes data and to share with employees what health plans want to do with data.</b></li> <li>▪ Insights generated could be used to intervene internally and to engage public officials for <b>community-wide impact.</b></li> </ul>	<ul style="list-style-type: none"> <li>▪ <b>Legal uncertainty</b> inhibits data sharing even when no legal barriers exist when data are used or shared for a permitted purpose.</li> <li>▪ Some <b>states have restrictions</b> on data sharing.</li> <li>▪ <b>Existing data-consent contracts</b> limit the ability to share data without further action.</li> <li>▪ Employees may worry employers could <b>use their identities against them</b>, especially when R/E data are collected at new hire onboarding, before trust has been built.</li> <li>▪ Some employers may assign <b>low priority</b> to data collection without regulatory consequences or clearer regulatory guidance, but additional regulatory requirements could be problematic.</li> <li>▪ Small and midsize employers (which employ most individuals) especially <b>lack resources for extensive databases.</b></li> </ul>	<ul style="list-style-type: none"> <li>▪ Widespread <b>understanding</b> of the lack of federal legal barriers needs to be achieved; state data laws should be amended.</li> <li>▪ Employers must <b>commit</b> to the business case for understanding and reducing inequities.</li> <li>▪ Employers should begin <b>getting consent</b> to share data from new hires.</li> <li>▪ <b>Incentives</b> for collecting and sharing R/E data, including confirmation of legal limitations, should be provided.</li> <li>▪ <b>Coordination</b> must be established across employer departments and with external partners administering health plan services.</li> </ul>
<b>State and federal health insurance programs</b>	<ul style="list-style-type: none"> <li>▪ Current procedures yield <b>higher rates of R/E data collection in public plans</b> than commercial plans.; e.g., R/E is asked on a voluntary basis during Medicaid enrollment.</li> <li>▪ Some states are testing <b>tools to incentivize data collection.</b><sup>a</sup></li> <li>▪ <b>Programs already have some R/E data</b> via other systems (e.g., birth, marriage) which can be merged in some data systems.</li> <li>▪ Push for collection of R/E in <b>Medicare Parts C and D</b> is underway.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Though R/E data for enrollees in traditional Medicare are relatively complete because of information from SSA records, voluntary race data categories from before 1980 were <b>limited</b> to white, black, other, and unknown and may have been imputed.</li> <li>▪ Medicaid and Marketplace data collection categories and completeness <b>vary</b> across states, paper vs. online applications, etc.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Broader adoption of data collection categories that <b>vary in granularity by local area but roll up to consistent standards</b> is needed.</li> <li>▪ Response rates may be higher if programs provide <b>justification</b> for R/E questions to encourage response and opportunities for individuals' questions.<sup>a</sup></li> <li>▪ State R/E data could be <b>audited</b> to identify gaps.</li> <li>▪ Programs could benefit from technical assistance and other funding for <b>improved data systems.</b></li> <li>▪ <b>Broader availability of funding</b> is needed for community health workers and navigators to build trust and increase data completeness.</li> </ul>

	Opportunities	Challenges	What could help?
Health plans	<ul style="list-style-type: none"> <li>Health plans have <b>large reach</b> across product lines, to both patients and providers, and across process touchpoints; unique opportunity exists to collect data from providers or during enrollment (plans already collect other data during application and enrollment).</li> <li>Health plans could achieve <b>standardization</b> across product lines, states, etc.</li> <li>Health plans have most comprehensive view of the claims and utilization for their members; serving as the collectors and aggregators of data could <b>remove employers from needing to solve consent and legal barriers</b>.</li> <li>Health plans have <b>relationships</b> with community-based organizations, navigators, assistors, etc.</li> <li>Plans could <b>reduce redundancy</b> in data collection from different providers if data are shared across health systems, following the patient across platforms and records (as one stakeholder described, collect the data <i>once</i> and use it <i>many times</i>).</li> </ul>	<ul style="list-style-type: none"> <li>Some consumers have <b>low trust</b> in plans (complexity of health system means consumers may not understand plans' role); the most trusted entity "will never be the health plan," according to one stakeholder.</li> <li>Plans <b>may not see marginal benefit</b> of improving self-reported R/E data collection when models can impute well enough to support population-level uses.</li> <li>Relying on plans <b>excludes uninsured people</b>.</li> </ul>	<ul style="list-style-type: none"> <li>Industry should <b>commit</b> to standardized, self-reported data collection (using best practices), which is preferred over imputation/AI.</li> <li>Smaller plans may need <b>technological support and guidance</b>.</li> <li><b>Safeguards</b> should be established and communicated to address privacy and discrimination concerns.</li> <li>Plans should be willing to <b>report on and address inequities</b> revealed in data.</li> <li>Plans should understand <b>transformation requires significant investments</b> but is urgently needed; upfront investments in equity could avoid costs down the line, potentially helping plans save on overall health costs in the long term.</li> </ul>

**Sources:** Summit on Race and Ethnicity Data Collection for Health Equity discussions and stakeholder interviews.

**Notes:** R/E = race and ethnicity. FQHC = federally qualified health center. EEOC = Equal Employment Opportunity Commission. DE&I = diversity, equity, and inclusion. SSA = Social Security Administration. AI = artificial intelligence.

<sup>a</sup> Colin Planalp, "New York State of Health Pilot Yields Increased Race and Ethnicity Question Response Rates" (Princeton, NJ: State Health and Value Strategies, 2021); Elizabeth Lukanen and Emily Zylla, "Exploring Strategies to Fill Gaps in Medicaid Race, Ethnicity, and Language Data" (Princeton, NJ: State Health and Value Strategies, 2020).

#### 4. Prioritize Organizational Capacity and Sufficient Resources to Collect, Analyze, Share, and Use Race and Ethnicity Data

Better communication of the value of improved R/E data collection and sharing could help encourage plans, employers, providers, and patients to act. Several stakeholders suggested a proof-of-concept approach, focusing on an issue with a well-established health disparity (based on complete data) where evidence suggests action has reduced disparities. Others suggested that employers wishing to share data with health plans could rely on employee resource groups or affinity groups to raise awareness of the importance of voluntary collection and to provide information on how to roll out such an effort. Overall, participants highlighted the importance of a cultural shift. One shared the following insight:

[When] incorporating race/ethnicity data collection into a company-wide health equity strategic plan...it's really critical that this effort doesn't get siloed to a small health equity team or office but is really incorporated into a larger strategic effort. [The organization could view] this collection as really foundational to achieving health equity, seeing it as the first step. [This would include] communicating the value-add to leadership...[and] reframing the collection of race and ethnicity data from a deficit space lens to [a] solutions space lens and really viewing this as an opportunity for...[the] organization to be a leader in this space.

But even after elevating R/E data collection and sharing among organizations' many competing concerns, major challenges will likely remain. For instance, though some participants maintained that data collection by employers would not likely be too burdensome using current workforce management technology, employers will need to broaden data consent agreements. For other organizations, incompatible data systems could present a major barrier. Summit participants suggested that crafting technological solutions may require additional federal support, such as from the US Department of Health and Human Services, and could require sufficient funding for collecting, storing, and using data and adequate training, or "supporting people to do this well," as one participant put it. One participant said such an effort could begin in a smaller way, such as with encouraging providers, employers, and plans to share limited data that are interoperable, and then build to broader efforts. Another described the need for a "transformational" chief executive officer to spearhead robust efforts in their organization, despite the financial costs; such a voluntary effort could lead to a domino effect of more organizations doing the same, eventually leading to broader efforts and even, over time, to mandated data collection.

# What Should Happen Now to Jumpstart Action?

According to the summit participants and stakeholders we interviewed, many opportunities exist for improved data collection and sharing to advance health equity. But in addition to achieving a broad understanding of the value of such efforts, participants indicated that the following should happen to catalyze change: multisector action should begin immediately, voluntary reporting should be resourced, and guardrails should be put in place to ensure data security and patient privacy and to prevent discrimination and other harms to individuals and groups.

## **1. Multisector Stakeholders Should Begin Working Together Immediately (but It Will Take Time to Achieve Needed Results)**

Action around the collection of R/E data by health plans should involve multisector collaborations and will likely take time to realize. Using R/E data to advance health equity may take even longer and require accountability and long-term commitments from the health care sector. Stakeholders and summit participants developed the following action steps to help jumpstart the process:

- Office of Management and Budget R/E standards should be updated to reflect the demographic diversity of the US, which the White House announced is currently underway. These standards should be considered a floor, rather than a ceiling, and allow for greater granularity that can roll up to Office of Management and Budget standards, and standards should apply across the federal government. Health plans can also build on federal efforts underway to update data standards and promote interoperability by quickly adopting such standards and offering input via public comment as standards are refined over time.
- Relevant federal agencies such as the Equal Employment Opportunity Commission and the US Department of Health and Human Services should work together to develop guidance about the ability of employers, providers, and community partners to share R/E data with health plans.
- Health plans should communicate to members, providers, and community partners the reasons they want to collect R/E data and how the data will be used to advance health equity. Engaging members and community partners about this early on, considering their concerns, and reporting back with real data can help build trust.
- States, health plans, providers, and community-based partners can benefit from resources for training staff and developing IT platforms that can safely collect and share data across multiple systems and organizations. Not only can these efforts be resource intensive, they will also take time to develop, so urgent action is likely needed.
- A new multisector coalition should be established (1) to advocate for policies that can advance greater collection of R/E data at the federal, state, and plan levels and (2) to educate

stakeholders about the importance of collecting these data, the ability of different entities to share data, and the guardrails needed to protect privacy and prevent harm.

## **2. Individual Reporting Should Be Voluntary and Organizations Collecting Data Should be Adequately Resourced**

Summit participants generally agreed that health plan members should not be *required* to share R/E data; reporting should remain *voluntary*. Entities that have multiple interactions with members should encourage self-identification and provide information about the importance of R/E data for advancing health equity in members' communities and how data will be used if members self-attest.

Some stakeholders and summit participants thought state Medicaid programs, health plans serving both commercial and public markets, and providers could also be encouraged to collect and share R/E data. Providing technical assistance, resources for training staff, and funding for the development of IT systems that facilitate collecting and sharing R/E data could encourage these entities, and some stakeholders identified the need for resources from the federal government or health plans for this work. Early adopters could potentially identify leading practices from which others can learn. Other summit participants believed it is past time for providers, health plans, and federal health insurance programs to voluntarily collect R/E data and that requirements to collect such data will ultimately be needed (but should be phased in).

## **3. Government Agencies, Health Plans, Employers, and Individuals Should Work Together to Develop Guardrails That Help Ensure Data Security and Patient Privacy and Prevent Harms to Historically Marginalized Groups**

Stakeholder interviewees and summit participants stated strongly that guardrails should be in place and clearly publicized to limit how R/E data can be used and shared and to ensure patient privacy. Though existing regulations prohibit health plans from discriminating based on the races and ethnicities of potential and actual members, summit participants stated clearly that people from historically marginalized groups may fear being discriminated against if they provide R/E information to health plans. Consequently, many participants agreed that informed consent is needed that describes in plain language who will have access to a person's data and how the data can be used.

Patient advocates were not the only stakeholders who raised concerns about consent. Some of the employers we interviewed raised the issue of employee privacy and lack of consent as, among other reasons, why they were unwilling to share with health plans the R/E data of their employees that they

collected for Equal Employment Opportunity Commission purposes. Several employers reported that even if they were told they could legally share employee R/E data, they would have to ask employees for their consent to do so. Some providers also mentioned that though they have successfully collected patients' R/E data, they do not share these data with health plans to maintain their patients' trust. Whether these practices represent employers and providers more generally is unclear, but they highlight some of the potential guardrails or permissions that may be needed.

Though summit participants emphasized that guardrails for using and sharing R/E data are needed, they did not broadly discuss the form those guardrails should take. However, some participants offered a few suggestions. First, stakeholders suggested that individuals and patient advocacy groups, along with other stakeholders, should be engaged in developing guardrails. This engagement could result in trust building and the reduction of unintended harms. Collaboration with other organizations working on informed consent to improve health equity could jumpstart this process. Second, health plans should be careful about disaggregating too much when releasing data to protect member privacy.

## Conclusion

Engagement with dozens of stakeholders identified significant interest across multiple sectors in improving the availability of high-quality, complete R/E data that can be used to detect, track, and evaluate efforts to close equity gaps. Stakeholders identified multiple opportunities for health plans to use such data to support interventions and proposed solutions to barriers related to trustworthiness, legal concerns, the lack of updated standards, and more. They also highlighted the need for urgent, multisector, and simultaneous action. Ultimately, summit participants described the potential for progress to build on itself; early action could show the value of R/E data collection efforts, thus encouraging broader endeavors that could then become universal. Such action will likely need to be a public-private partnership across and within organizations including health plans; federal and state governments; employers; health care providers; technology firms; foundations; and advocacy, public health, provider, and research organizations.

Importantly, many stakeholders emphasized the need to include the perspectives and input of individuals and enrollees; one participant described this as “listening to the needs of the community.” We heard repeatedly that consumers—who own the data in question—are often excluded from discussions about R/E data collection, sharing, and use, and that they should have a say in how those data are collected and used and which guardrails should be developed for their protection. Thus, stakeholders viewed incorporating community engagement and trusted community partners in efforts

to improve data collection as essential. This type of engagement is an important first step for health care institutions to gain the trust of marginalized groups who have historically been and currently are being harmed and to prevent future unintended consequences.

Study participants also identified several specific priority steps toward improving R/E data collection and use, including getting stronger signals from the federal government clarifying the legality of data collection and sharing with private health plans; developing transparent communication about the reasons for collecting such data; creating and sharing guardrails to ensure data security and prevent harm among historically marginalized groups; developing more inclusive standards for self-reported, voluntary identification; and investing in updated, interoperable data systems and training for frontline workers.

Stakeholders also emphasized the need for tools to propel further action, including a detailed legal summary of federal and state laws that can help reduce concerns around data collection and sharing. They also noted that R/E information is just one element of long-standing structural inequity and similarly stressed that improving R/E data collection is just one step that should eventually be broadened to include other factors that affect health care experiences and outcomes.

Despite the many opportunities and momentum for improved data collection, study participants acknowledged that data collection alone will not eliminate health inequities. First, data should be collected and shared across organizations; doing so requires considerable investments in consistent data collection standards, shared regulatory and legal guidance, and technological advances to update outdated data systems and support interoperability, which will likely require strong leadership and substantial resources. Moreover, such efforts may be futile if they are not followed by interventions and the will to make changes in health care delivery and access to close equity gaps.

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*We're beyond the 'consider' moment, we are beyond the 'did you know?' moment....What are we going to actually do with this information?*

*—Summit participant*

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# Notes

- <sup>1</sup> [Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity](#), 58782 Fed. Reg. 62 (Oct. 30, 1997).
- <sup>2</sup> Dania Palanker, Jalisa Clark, and Christine Monahan, "Improving Race and Ethnicity Data Collection: A First Step to Furthering Health Equity through the State-Based Marketplaces," Commonwealth Fund blog, June 9, 2022, <https://www.commonwealthfund.org/blog/2022/improving-race-and-ethnicity-data-collection-first-step-furthering-health-equity-through>.
- <sup>3</sup> Karin Orvis, "Reviewing and Revising Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity," White House Briefing Room, June 15, 2022, <https://www.whitehouse.gov/omb/briefing-room/2022/06/15/reviewing-and-revising-standards-for-maintaining-collecting-and-presenting-federal-data-on-race-and-ethnicity/>.
- <sup>4</sup> Paige Minemyer, "CMS Puts Focus on Health Equity in Medicare Advantage, Part D Advance Notice," *Fierce Healthcare*, February 3, 2022, <https://www.fiercehealthcare.com/regulatory/cms-puts-focus-health-equity-medicare-advantage-part-d-advance-notice>; "Health Equity Accreditation Programs," National Committee for Quality Assurance, accessed June 17, 2022, <https://www.ncqa.org/programs/health-equity-accreditation/>.
- <sup>5</sup> Centers for Medicare & Medicaid Services, "Accountable Care Organization (ACO) Realizing Equity, Access, and Community Health (REACH) Model," news release, February 24, 2022, <https://www.cms.gov/newsroom/fact-sheets/accountable-care-organization-aco-realizing-equity-access-and-community-health-reach-model>.
- <sup>6</sup> The summit participant shared illustrative language for respondents, including the following: (1) "We need your help! Please take one minute to tell us your race, ethnicity, and language preference. Only you can provide this information, which will help improve the quality of care for everyone we serve. We'll use the race, ethnicity, and language information you provide to measure, understand, and reduce inequities in health care. Your answers will be combined with other members' data to improve our programs and services. Providing this information—or choosing not to provide it—will have no effect on the coverage you receive." (2) "We are collecting this information to find out who we serve and help us improve health care for our members. Sharing this information is completely voluntary and will be kept confidential. Participating—or choosing not to—will have no effect on the coverage you receive....Thank you for taking this important survey."
- <sup>7</sup> "EEO-1 Data Collection," US Equal Employment Opportunity Commission, accessed June 16, 2022, <https://www.eeoc.gov/employers/eo-1-data-collection>.
- <sup>8</sup> Current federal guidance includes the Office of Management and Budget's 1997 format based on separate race and ethnicity questions with 5 race options (see [Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity](#), 58782 Fed. Reg. 62 [Oct. 30, 1997]) and the US Department of Health and Human Services/Centers for Medicare & Medicaid Services format (ASPE 2011), which uses separate race and ethnicity questions with 14 race options.
- <sup>9</sup> Nancy López, "What Is 'Street Race'?", University of New Mexico, Institute for the Study of "Race" and Social Justice, accessed July 14, 2022, <https://race.unm.edu/what-is-street-race.html>.

# Appendix. Potential Legal Barriers to the Collection, Storage, Use, and Disclosure of Participant Race, Ethnicity, and Language Data by Group Health Plans and Group Health Insurance Issuers

By Seth Perretta, Christy Tinnes, and Katelyn Davis, Groom Law Group Chartered; and James Paretti, Littler Mendelson P.C.

Calls to consider the potential disparities in care among individuals based on race, ethnicity, and language (REL) have recently been made, yet it seems group health plans and issuers have often been reluctant to request these data. In fact, a recent study that used 2015 Healthcare Effectiveness Data and Information Set data found that commercial health plans lagged behind Medicare and Medicaid in tracking REL data. This owes, at least in part, to the Affordable Care Act (ACA) requiring Medicare and Medicaid plans to answer questions based on REL data as part of reporting but not requiring the same of employer group health plans or private commercial coverage (Ng et al. 2017).

In connection with these recent calls to action, questions have arisen regarding whether legal or other barriers may exist that prohibit and/or discourage the collection, storage, use, or disclosure of REL data for reducing potential disparities in health care. This appendix summarizes research findings regarding the extent to which applicable laws (including regulations and subregulatory guidance) may pose actual or perceived legal barriers to the collection, storage, use, or disclosure of REL data by group health plans (GHPs) or commercial group health plan insurers (GHIs).<sup>1</sup>

As discussed in greater detail below, we did not identify specific state or federal laws applicable to GHPs and GHIs that would expressly bar or prohibit the collection, storage, use, or disclosure of REL data as long as such data are collected for a permitted purpose; for this analysis, the “assumed admitted purpose” is reducing health disparities. However, we suspect that the *perception* of legal barriers and the uncertainty of *whether* such legal barriers exist may discourage some GHPs or GHIs from requesting or collecting REL data. These concerns may also foster reticence in individuals when they are confronted

with a request for REL data. Additionally, we suspect that GHPs and GHIs may be concerned that the collection of REL data, even for the assumed permitted purpose, may increase litigation risks and/or related litigation costs; the collection and possession of REL data may make it more challenging to successfully dispense of such litigation at the early motion stage.

## Federal Law Analysis

Of note, the major federal statutes that address the provision of health care benefits and health insurance coverage by GHPs and GHIs do not include express limitations on the collection, storage, use, or disclosure of REL data for the assumed permitted purpose. Nor do these statutes include provisions expressly requiring or permitting GHPs and GHIs to collect, store, use, or disclose REL data. These statutes include the Public Health Service Act (PHSA),<sup>2</sup> the ACA (including section 1557),<sup>3</sup> the Employee Retirement Income Security Act (ERISA),<sup>4</sup> the Internal Revenue Code (IRC),<sup>5</sup> the Health Insurance Portability and Accountability Act (HIPAA),<sup>6</sup> and the Genetic Information Nondiscrimination Act.<sup>7</sup>

Perhaps surprisingly, the HIPAA privacy rules also do not expressly bar the *collection* of REL data.<sup>8</sup> However, they generally *would* consider REL data to be protected health information when collected by a health plan. As such, a GHP or GHI would be limited in how it could *use or disclose* these data, even when free to collect such information. REL data also could cause information that a health plan may believe to be deidentified to not meet the HIPAA deidentification standards, because race or ethnicity could be unique characteristics that could be used to identify an individual. For example, even if all of the required fields from the HIPAA deidentification safe harbor are removed, HIPAA also requires that the covered entity not have knowledge that the remaining information could still be used alone, or in combination with other information, to identify an individual.<sup>9</sup> In a small enough population or in the context of other unique characteristics, such as a particular condition, there could be a risk that combining the underlying data with the additional REL data could cause the underlying information to be considered identifiable under HIPAA standards.

Though the HIPAA rules generally should not prohibit the collection, storage, use, or disclosure of REL data for the assumed permitted purpose, we suspect that at least some GHPs and GHIs may be reluctant to request REL data over uncertainty regarding whether HIPAA prohibits doing so. GHPs and GHIs may also be concerned that collecting this additional information could create a risk in the event of a security breach regarding the storage and/or use of such data.

In addition, to the extent that a GHP or GHI seeks to collect REL data for use in discriminating *against* individuals based on a health factor, this would generally be prohibited by HIPAA nondiscrimination rules.<sup>10</sup> For example, a GHP or GHI could seek to collect REL data for use in charging certain populations higher premiums for coverage because of a given chronic condition being more prevalent in a certain racial minority group. If that GHP or GHI then used the collected data to charge higher premiums, this would seem to violate HIPAA's nondiscrimination rules. However, if the REL data are collected for the assumed permitted purpose, the HIPAA nondiscrimination rules generally would *not* bar the collection, storage, use, and disclosure of REL data.

Further, numerous federal laws prohibit discrimination in the employment context, including most notably Title VII of the Civil Rights Act of 1964 (Title VII),<sup>11</sup> which prohibits discrimination based on race and ethnicity. Based upon our review, these federal employment-based nondiscrimination laws (including related implementation and enforcement guidance from the Equal Employment Opportunity Commission) do not appear to be an actual legal barrier to the collection, storage, use, or disclosure of REL data for the assumed permitted purpose. In fact, we note that Title VII (and certain federal contracting requirements) requires certain employers to collect data on the race and ethnicity of their workforce, specifically in connection with the completion and submission of the EEO-1 Report.<sup>12</sup> Notwithstanding the absence of an actual legal barrier, some employers could perceive the collection of REL data or use of collected REL data (e.g., data collected as part of EEO-1 compliance) as violating one of these federal laws, even where the REL data would be used for the assumed permitted purpose. Employees' general awareness of the existence of these laws could also cause some employees to question the legality of their employers' needs to request or basis for requesting REL data. In turn, this could also contribute to some employers being reluctant to collect or otherwise use REL data for the assumed permitted purpose. Additionally, the fact that a GHP (or its associate) may possess REL data may make it more difficult for an employer-plan sponsor to dispense of certain plaintiff or class claims at the early motion stage (such as motion to dismiss). This is because in cases involving alleged discriminatory intent, the employer may no longer be able to assert that it lacked knowledge of the plaintiff's or plaintiffs' specific REL data (and, therefore, could not have acted with discriminatory intent).

There are numerous other nondiscrimination laws at the federal level, including the Americans with Disabilities Act, ACA section 1557, and HIPAA's nondiscrimination provisions (as discussed above). Significantly, we did not identify in these other federal nondiscrimination laws any specific barriers regarding the collection, storage, use, or disclosure of REL data for the assumed permitted purpose. As noted above with respect to the federal employment-based statutes, we suspect that some GHPs and

GHIs may be reluctant to request REL data to avoid the perception or inference that they may be discriminating based on race or ethnicity in providing health benefits (even where that is not the case). Thus, although the collection of certain REL data may be helpful for targeting additional medical care or plan benefits to participants who may be at a higher risk of a condition based on their race or ethnicity, a GHP or GHI may nonetheless be reluctant to request such data. Moreover, as noted above, to the extent that a GHP or GHI possesses REL data, it may make it harder for the GHP or GHI to successfully dispense of litigation at the early stages based on the fact that the entity possesses such data. Further, no federal statute prohibits an employer from sharing the REL data it collects for other purposes with GHPs, third-party administrators, or GHIs, but employers may be reluctant to share such data for the reasons described above.

## State Law Analysis

The potential application of state laws to GHPs varies depending on whether a GHP is self-funded. This is because ERISA includes an express statutory provision preempting all state laws that relate to an ERISA-covered plan, except for state laws relating to insurance, banking, and securities.<sup>13</sup> Consequently, state-level insurance laws generally will not apply to self-funded GHPs and thus should not impede the collection, storage, use, and disclosure of REL data for the assumed permitted purpose.

In contrast, with respect to fully insured GHPs and GHIs, state insurance laws are much less likely to be preempted. Thus, it is conceivable that these types of laws could (now or in the future, based on future state rulemaking) pose a barrier to the collection, storage, use, or disclosure of REL data for the assumed permitted purpose. Nonetheless, based on our canvassing of state insurance laws and review of related secondary sources, state insurance laws do not currently appear to pose a legal barrier to the collection, storage, use, or disclosure of REL data for the assumed permitted purpose, even with respect to insured GHPs and GHIs.

We did, however, identify numerous state laws that address the *collection* of REL data by insurers. Though some of these laws prohibit an insurer from collecting REL data *before* enrollment, they do not appear to restrict an insurer's ability to collect such data *after* enrollment.<sup>14</sup> Interestingly, we also identified other state insurance laws that *mandate* the collection of REL information.<sup>15</sup> Though we identified state insurance laws that limit the *use* of REL data for discriminatory purposes, we did not identify any such laws that would bar the collection, storage, use, or disclosure of REL data for the assumed permitted purpose.<sup>16</sup>

State privacy laws do not appear to bar the *collection* of REL data; however, they may place additional limits on how such data are stored, used, or disclosed.<sup>17</sup> Notably, the HIPAA privacy rules generally do not preempt state privacy laws, unless the state law is contrary to, or otherwise interferes with, the application of HIPAA. Because HIPAA generally serves as a federal “floor” on privacy issues, states certainly *could* adopt more stringent state privacy laws that could restrict a GHI’s collection, storage, use, or disclosure of REL data, even for the assumed permitted purpose.

Lastly, it is important to note that state laws may vary significantly. Numerous organizations, such as the National Association of Insurance Commissioners, exist to develop model statutes for use by individual states. Nevertheless, statutes vary significantly across states, even within a given subject matter (such as health plan privacy). Given this variability and the significant financial costs that may be incurred in tracking and monitoring these state laws, we suspect that at least some GHIs may be reluctant to request REL data because of a lack of clarity regarding if and how state insurance laws may impede the collection, storage, use, or disclosure of such data, even for the assumed permitted purpose.

## Overall Findings

Our review did not identify specific state or federal laws that pose legal barriers to the collection, storage, use, or disclosure of REL data for the assumed permitted purpose of reducing health care disparities. Still, we suspect *perceived* legal barriers may discourage GHPs and GHIs from requesting and collecting REL data and may discourage employers from sharing REL data with GHPs, third-party administrators, and GHIs. These perceived legal barriers may also foster among individuals a reticence to provide personal REL data when they are requested. In addition, the overall uncertainty among GHPs and GHIs regarding *whether laws may exist* that would prohibit the collection of REL data (especially at the state level, with respect to GHIs) may affect the collection or use of such data. Some employers, and perhaps GHIs, also may be concerned that collecting REL data and sharing them with GHPs, third-party administrators, and GHIs may increase their litigation risks and their costs of litigation.

## Notes

<sup>1</sup> For the purposes of this summary and our underlying research, GHIs encompass large- and small-group health insurance that constitutes “minimum essential coverage” as described in the Internal Revenue Code section 5000A.

<sup>2</sup> See generally 42 U.S.C. §§ 300gg to 300gg-139.

- <sup>3</sup> See generally Patient Protection and Affordable Care Act, Pub. L. No. 111-148 (2010) and underlying regulations.
- <sup>4</sup> See generally 29 U.S.C. §§ 1181 to 1191d.
- <sup>5</sup> See generally 26 U.S.C. § 9801 et seq.
- <sup>6</sup> See generally 29 U.S.C. Part 7 (nondiscrimination provisions at 29 U.S.C. § 1182 et seq.).
- <sup>7</sup> See generally 29 U.S.C. § 1182 et seq. (Title I); 42 U.S.C. § 2000ff et seq. (Title II).
- <sup>8</sup> See generally 45 C.F.R. Parts 160–164.
- <sup>9</sup> See 45 CFR § 164.514(a)(2)(ii).
- <sup>10</sup> See generally 29 C.F.R. § 2590.702 et seq. (with corresponding regulations under the PHS Act and the IRC).
- <sup>11</sup> 42 U.S.C. § 2000e.
- <sup>12</sup> 42 U.S.C. § 2000e-8(c); 29 C.F.R. §§ 1602.7 to 1602.11 (requiring employers with 100 or more employees to submit demographic workforce data, including on race and ethnicity, sex, and job categories, to the Equal Employment Opportunity Commission).
- <sup>13</sup> 29 U.S.C. § 1144.
- <sup>14</sup> See Cal. Ins. Code § 679.72 (“No application for insurance...shall carry any identification” of an individual’s sex, race, color, religion, ancestry, national origin, disability, medical condition, genetic information, marital status, sexual orientation, citizenship, or primary language); Md. Code Ann. §§ 27-501, 27-502 (explaining neither an insurer nor a surety may make an inquiry about race, creed, color, or national origin on an insurance form or questionnaire); N.H. Code Admin. R. Ins. § 401.12(e) (“Questions as to race or ethnicity shall be prohibited.”); 31 Pa. Code § 89.12 (prohibiting questions about race and color on a health insurance application).
- <sup>15</sup> See Ark. Code Ann. §§ 20-7-303, 20-7-305 (requiring the Department of Health to collect and disseminate health data); Cal. Health and Safety Code § 127673 (mandating the provision of personal health information, including age, gender, gender identity, race, ethnicity, sexual orientation, health status, or health condition by insurers and self-insured health plans to the Department of Public Health); Kan. Admin. Regs. § 28-67-2 (noting the Department of Health and Environment shall collect information regarding various health factors, including demographics); 957 Mass. Code Regs. 8.03 (requiring insurers to submit certain information to the all-payer claims database); 590-243-2 Me. Code R. § 2 (explaining health care claims processors shall submit claims data, including REL data, to the Department of Health and Human Services); 35 Pa. Const. Stat. § 449.6 (requiring health maintenance organizations, commercial insurers, and self-insured employer plans to submit a patient’s sex and race, in addition to other claims-related information, to the Health Care Cost Containment Council).
- <sup>16</sup> See, for example, Ark. Code Ann. § 23-66-205 (states that “no person shall engage in...an unfair method of competition or an unfair or deceptive act or practice...in the business of insurance...” and defines unfair discrimination as “refusing to insure or continue to insure an individual solely because of the individual’s race, color, creed, national origin, citizenship, status as a victim of domestic abuse, or sex”); D.C. Code § 31-2231.11 (outlawing discrimination in the availability of any policy, underwriting practice, or eligibility standard on the basis of race, religion, nationality or ethnic group, age, sex, family size, occupation, place of residence, or marital status); Kan. Stat. Ann. § 40-2404 (noting insurers may not engage in unfair discrimination between individuals of the same class and of the same hazard in the amount of premiums, policy fees, or rates charged for any health insurance policy); Me. Rev. Stat. tit. 24-A, § 4320-L (“A carrier may not in offering, providing or administering a health plan deny, cancel, limit or refuse to issue or renew a health plan...on the basis of race, color, national origin, sex, sexual orientation, gender identity, age, or disability...”); N.H. Rev. Stat. § 417:4 (describing that refusing to insure risks solely because of race, color, creed, national origin, ancestry, or marital status constitutes an unfair trade practice); N.Y. Ins. Law §§ 2606-2607 (prohibiting insurers from making distinctions between persons by race, color, creed, national origin, disability, sexual orientation, or gender identity in the premiums or

rates charged for insurance policies); N.D. Cent. Code § 26.1-04-03 (defining unfair competition, in part, as “refusing to insure risks solely because of race, color, creed, sex, or national origin”); Wash. Admin. Code § 284-43-5940 (explaining that an insurer may not deny, cancel, or refuse to issue a policy, impose additional cost sharing, impose other restrictions on coverage, or limit benefit designs on the basis of race, color, national origin, sex, gender identity, sexual orientation, age, or disability); W.Va. Code § 33-25A-14a (“No [health maintenance organization] shall discriminate in enrollment policies or quality of services against any person on the basis of race, sex, age, religion, place of residence, or source of payment...”).

<sup>17</sup> See, for example, Ark. Code Ann. § 20-7-301 et seq. (permitting the Department of Health to release data collected for the State Health Data Clearing House, except released data “shall not include any information which identifies or could be used to identify any individual patient, provider, institution or health plan”); Iowa Admin. Code R. 641-177.6 (76GA, ch1212); Kan. Admin. Regs. § 28-67-4.

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