Live at Urban | July 20, 2022

Improving the Collection of Race and Ethnicity Data for Health Plans to Advance Health Equity

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Deloitte.

Overview of “Collection of Race and Ethnicity Data for Use by Health Plans to Advance Health Equity: Opportunities, Barriers, and Solutions”

Jennifer Haley, Urban Institute

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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Introduction

- Extensive evidence of **disparate health outcomes by race and ethnicity**; **momentum for addressing health equity**
- **Health plans' unique position** to use data to advance health equity
- **Limited access** to high-quality race and ethnicity data: variation, incompatibility, inability to disaggregate
- Research assessed stakeholders' suggestions for **how to improve the collection of race and ethnicity data for use by health plans** and identified **high-priority next steps**

Five key barriers

1. Lack of understanding and communication of the **opportunities** of improved data collection for health plans to advance health equity
2. Individuals' **trust**
3. **Legal concerns** and uncertainty
4. Outdated **data collection practices**
5. Insufficient organizational and resource **prioritization**

Clarify value of improved race/ethnicity data collection

- Potential opportunities for health plans to use data to address health equity include:
  - Conducting internal **monitoring of health equity patterns and trends**
  - **Public reporting** of providers' and plan-level health equity outcomes for **accountability**
  - Identifying where **additional health care resources** are needed
  - Conducting research to guide the **design and evaluation of interventions**
  - Detecting **potential bias in algorithms** that identify treatment decisions

Build consumer trust and enhance community engagement

*"We talk about lack of trust ….related to the individual from an individual context. And really it is **institutional trustworthiness, and lack of trustworthiness, that is a problem**." – Summit participant*

- Solutions include:
  - Bringing individuals/communities into the development of both **data collection practices** and **guardrails**
  - Incorporating **trusted community partners** who may be most effective at collecting information from historically marginalized people
  - Being **transparent** about how data would be used
  - **Sharing identified disparities** back to the community and engaging communities in **developing solutions** to health inequities

Reduce actual and perceived legal concerns and uncertainty

- Participants identified **legal concerns about data sharing**, such as among employers, as a key barrier
- But a legal analysis found **few legal barriers** to data collection and sharing with health plans, making **eliminating misconceptions** about legal barriers critical to encouraging more data sharing by employers
- For instance, summit participants identified the need for **clarification from the federal government**, such as guidance from appropriate federal agencies, describing legality and permissibility

Update and standardize self-reported race and ethnicity data collection practices

- Stakeholders maintained data collection standards should:
  - Be **self-reported**
  - Include **multiple categories** with instructions to “select all that apply,” perhaps with sequencing for preferred identities
  - Be **disaggregated** for smaller subgroups
  - Be **consistent** across states and organizations but be **varied in detail**
  - Be **voluntary for individuals,** including an option such as “**prefer not to disclose**”

Update and standardize self-reported race and ethnicity data collection practices

- **Community input** is needed for developing more inclusive standards for identification that reflects community identities
- Include investments in **updated, interoperable data systems**
- **Further collaborative work** is needed to:
  - Identify **which entities** could collect data to be shared with other sectors
  - Determine how data will be shared (**interoperability**)
  - Address **questions** about reducing redundancy, indicating sources of data, identifying preferred identity when sources disagree, and other best practices

Prioritize capacity and resources to collect, analyze, share, and use race and ethnicity data, and jumpstart action

"[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****." – Summit participant*

- Need for a **"cultural shift"**
- **Multisector, collaborative effort**
  - **Urgent/immediate action** (but it will take time)
  - **Sufficient resources**
  - **Guardrails** to ensure security/privacy and prevent harm

Legal Analysis and Employer Perspectives on Data Collection and Sharing

James Klein, American Benefits Council

Employer perspectives confirm presumption of barriers

- **American Benefits Council conducted an informal survey of large employers,** receiving responses from 44 unique organizations
- Twenty-six of the 44 organizations **currently collect race and ethnicity data in their capacities as employers**, in addition to collection required by EEOC; five of these organizations also collect race and ethnicity data in their capacities as self-insured health plans
- Among the organizations that do not collect race and ethnicity data, commonly cited reasons were **"expected employee hesitancy/reluctance"** and **"concerns about potential litigation"**
- Fifteen employers that collect race and ethnicity data **do not share the data** with anyone
- Eleven employers that do not share data with health plans indicated that "**understanding the health plan's intended use of this data**" would be a prerequisite for doing so
- Among organizations that don't collect data at all and those that collect but do not share it, the most commonly cited reason was **"perceived/presumed legal barriers"**

What federal laws govern race/ethnicity data collection/sharing by employers?

- **No prohibition on *collection, storage, use, or disclosure* of race/ethnicity data** by group health insurance/plans (whether insured or self-funded) for this purpose
- **No prohibition on *sharing* of race/ethnicity data** with group health plans, insurers, or third-party administrators

What state laws govern race/ethnicity data collection/sharing by employers?

- **State law generally does *not* apply to self-funded group health plans –** no legal barrier applies
- **State law generally *does* apply to insured health plans** – *could* pose barrier
  - Some **state insurance laws** prohibit race/ethnicity data collection *during* enrollment, but analysis did not find laws prohibiting collection *after* enrollment, and some laws, in fact, *mandate* race and ethnicity data collection
  - **State privacy laws** do not appear to bar race/ethnicity data collection by group health plans insurers but may place additional restrictions on use/disclosure (as states are permitted to impose restrictions beyond those in HIPAA)

Reality vs. perception

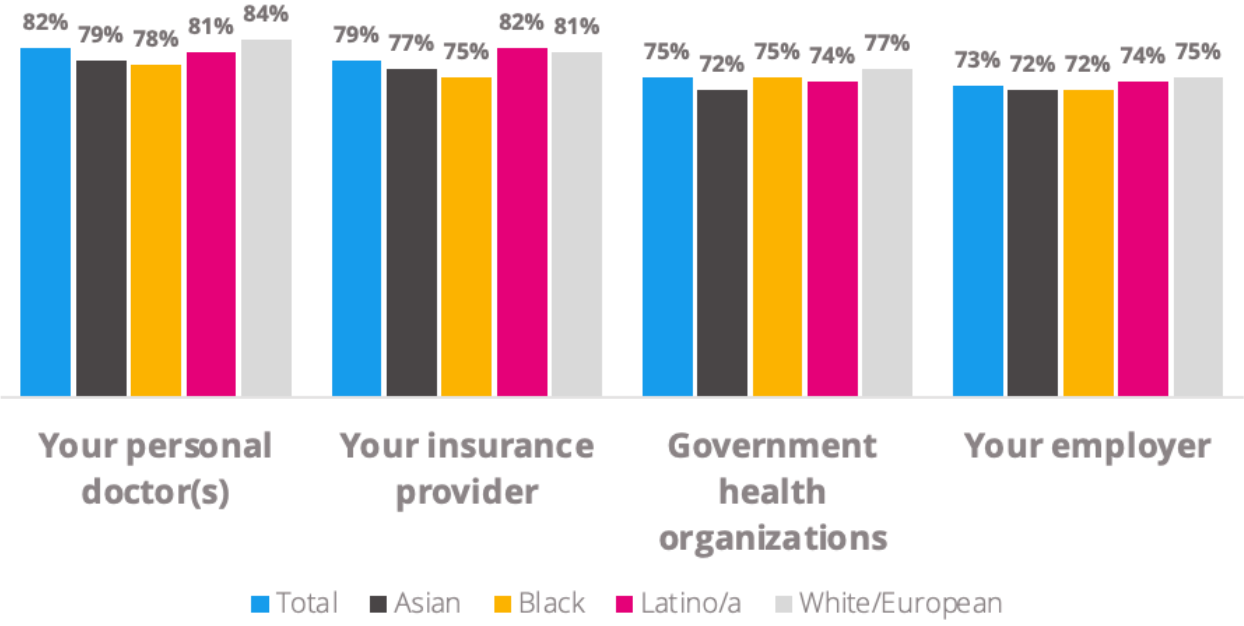
Despite few legal barriers on use of race and ethnicity data to promote health equity, several factors discourage employers from doing so:

- **Perception of legal barriers** discourages requesting/collecting/sharing
- **Numerous and variable state laws** create uncertainty of whether a law exists and potential inconsistency with another state's law
- **Litigation risks**
- **Data privacy and cybersecurity risks**
- **Public relations risks** associated with perception of racial profiling

Individual Perspectives on Data Collection and Sharing

David Rabinowitz, Deloitte

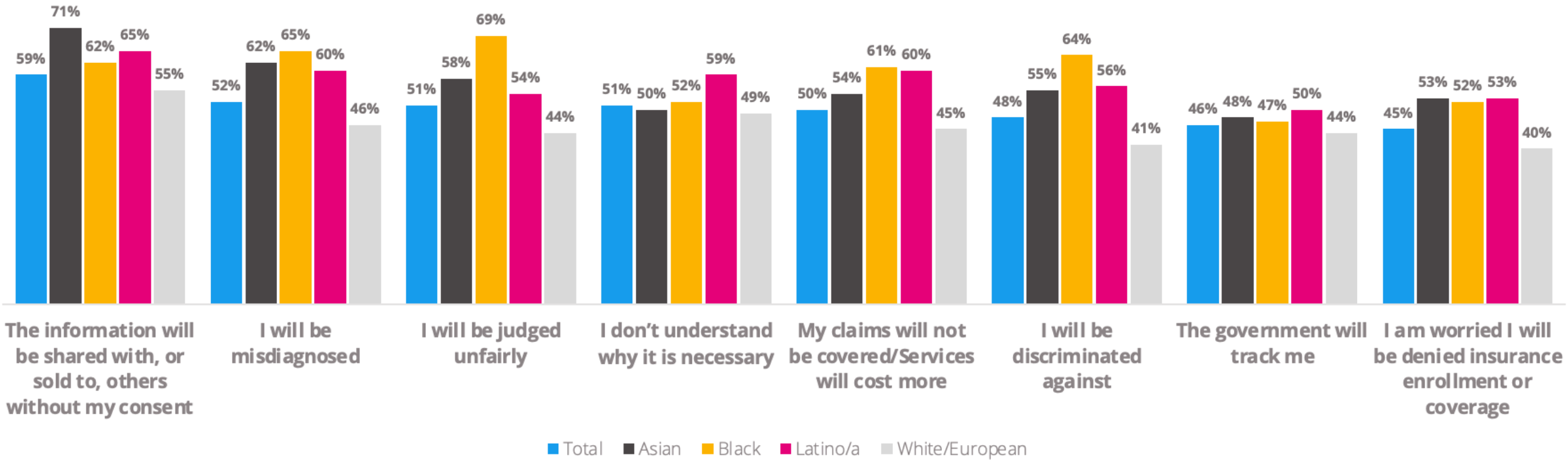
Survey: Majority comfortable sharing their race and ethnicity with doctors, plans, government, and employers



- Deloitte engaged a sample of **n=3,327** respondents in an online convenience sample survey
- **80%** are comfortable sharing their race and ethnicity with their health plan
- **6%** would be uncomfortable sharing
- White people were **slightly more comfortable** sharing than other racial and ethnic groups

Source: Drawn from a voluntary response convenience sample weighted to match the racial/ethnic 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. n=3,327.

However, privacy and data usage concerns exist, especially among nonwhite respondents



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These findings represent an important voice in the discussion

- People **may be more willing** to share their race and ethnicity with health plans than rates of current collection of these data suggest
- Though willingness to share data was high for all the subgroups examined, there were **differences across racial/ethnic groups**, such as in concerns about how data will be used
- **Data privacy and security concerns** should be addressed to build confidence and trust
  - Recognize that **there may be differences across racial/ethnic groups** regarding willingness to provide information to the health care system, and design strategies that recognize past and current harms by the health system accordingly
  - **Explain how data will and will not be used**

Panel Discussion

Shantanu Agrawal, Elevance Health

Nicole Evans, National Academy for State Health Policy

Shyloe Jones, Families USA

Carole Mendoza, Voya Financial

Brian Smedley, Urban Institute

Followed by Q&A