



Disparities in Data

Solutions and Barriers to
Implementation



INTRODUCTION

The COVID-19 pandemic shed light on gaps in health data and how those gaps can perpetuate racial and ethnic disparities in health outcomes. Research, including literature reviews and subject matter expert interviews spearheaded by PhRMA, have shown that failure to properly collect race and ethnicity data has been a known - but unaddressed -- problem for decades.ⁱ Based on that research, PhRMA recently released a paper detailing some of the challenges to proper data collection, including the inadequacy of data currently collected, technological barriers to collecting better data, and apprehension from both providers and patients regarding the collection or provision of data.ⁱⁱ

Underpinning these challenges is systemic racism - the root cause of health disparities and the difficulties we face in eliminating them.

In this paper - the second in a series on the implications of race and ethnicity data gaps - we review some proposed solutions for addressing the data collection challenges outlined above and discuss barriers to implementation. The solutions are representative of proposals by subject matter experts, government agencies, and public policy stakeholders, and reflect a great deal of thinking on this issue and include some known best practices. The proposals are not exhaustive, however, and we have made no determination regarding their effectiveness in generating better data or eliminating health disparities.

Despite the multitude of proposed

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solutions and calls to action, little progress has been achieved to date. Our research revealed several barriers to action. Similar to the proposed solutions, the barriers discussed are not exhaustive. Instead, we discuss barriers that are common to some of the proposed solutions. These barriers do not exist in a vacuum, but are connected and compound upon one another.

Closing gaps in the availability of race and ethnicity data is crucial to reducing disparities in health outcomes. Once systemic racism is recognized and highlighted as both the root cause of racial and ethnic health disparities and the reason there is a lack of urgency to do everything possible to eradicate them, efforts around data collection can be refocused and actionable solutions can be implemented through-out the health system.

COLLECTING RACE AND ETHNICITY DATA IN THE HEALTH CARE SYSTEM: CHALLENGES AND POTENTIAL SOLUTIONS

Challenge 1 - The types of data being collected are not standardized, mandated, or granular

The Institute of Medicine (IOM) released its report *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement* in 2009.ⁱⁱⁱ The report included many recommendations that could lead to more voluminous and more accurate health data reporting, with an aim toward improving health disparities linked to race and ethnicity.^{iv} In its report, IOM touches on standardization, granularity, and mandates. The three issues are interwoven - especially standardization and granularity - and all three must be addressed for progress to be made.

Standards and Granularity

One recommendation suggests the United States Department of Health

and Human Services (HHS) develop a national standard list of ethnicity categories at a granular level.^v While HHS has encouraged collection of more granular data than the minimum standards currently required by the Office of Management and Budget (OMB), it has not yet provided guidance to aid in standardization.^{vi} In its recommendation, IOM provided a template for determining a national standard list, which included more than five hundred distinct ethnicity categories. In contrast, only two ethnicity categories appear on the standard list developed by OMB.^{vii}

IOM does not suggest the solution to standardization is that every entity collecting health data include each of its recommended categories. Instead, it recommends that data collectors use the categories that are most relevant to the locale where the data collection or survey takes place. Having predefined, standard categories available for use could facilitate both broad analysis and more localized interventions.

IOM also recommends having HHS and the Office of the National Coordinator for Health Information Technology (ONC) adopt standards for the inclusion of race and ethnicity information in electronic health records and standards for electronic data transmission that can reduce duplicative and redundant information.

Mandates

Standards alone, even very granular standards, are not a panacea to better data collection. In addition to its recommendations about standardization, IOM recommends several methods for ensuring that the data are collected in the first place.^{viii}

These recommendations include efforts



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that can be made by federal agencies, such as requirements that all recipients of HHS funding and all federally funded health care delivery systems include data on race and ethnicity in individual health records, and that the payment of incentives must take into account collection of the same. Health data is collected by a wide variety of entities, including federal, state, and local governments; hospitals and other providers; and health insurers, so those entities must also be addressed.^{ix} (See Appendix A) IOM suggests that states, in their capacity as regulators, should require the same standards as those that govern the collection of federal race and ethnicity data. Likewise, IOM includes a recommendation that health accreditation organizations include similar requirements in their accreditation and performance measure standards.

Challenge 2 - Data collection systems are outdated and do not allow for interoperability

The interoperability of health information systems has been identified as an

important component in addressing health disparities.^x The inability to link and share information across care delivery settings and payors can result in large gaps in actionable data. Several measures have been proposed over the last decade to encourage providers and other data collecting entities to implement more advanced technology.

Increased Use of Certified Electronic Health Record Technology (CEHRT)

In 2011, CMS established the Promoting Interoperability Programs initiative to measure the use of CEHRT and encourage its adoption by providers and hospitals. The initiative was implemented in three stages, and Stage 2 focused on ensuring that meaningful use of the technology supported the aims and priorities of HHS' National Quality Strategy (NQS).^{xi} Notably, one of the NQS foundational principles is eliminating racial and ethnic health disparities.^{xii}

CMS Interoperability Milestones

- **Stage 1:** Established requirements for the electronic capture of clinical data, including providing patients with electronic copies of health information.
- **Stage 2:** Focused on advancing clinical processes and ensuring that the meaningful use of EHRs supported the aims and priorities of the National Quality Strategy and encouraged the use of CEHRT for continuous quality improvement at the point of care and the exchange of information in the most structured format possible.
- **Stage 3:** Focused on using CEHRT to improve health outcomes and modified Stage 2 to ease reporting requirements and align with other CMS programs.

Payment Incentives

The ONC develops interoperability standards and best practices to promote the access and exchange of electronic health information.^{xiii} ONC's interoperability initiatives focus on improving community health and recognize the impact of social determinants. To achieve the ability to seamlessly share data to further the understanding of disparities, one solution ONC has suggested is the use of financial incentives to promote interoperability in both the public and private sectors. Incentives may range from encouraging the use of electronic health information exchange and certified health IT to requiring their use as a condition of participation in certain Medicare payment models.^{xiv}

Challenge 3 - Providers and patients are apprehensive about race and ethnicity data collection

Providers

Health care providers, their staff, and others working in the health care delivery system (e.g., health plan personnel) cite concerns about the usefulness and legality of collecting race and ethnicity data. These concerns can hinder collection of patient race and ethnicity information – especially self-reported information that many researchers believe is the most accurate.

Implicit Bias Training

Addressing implicit bias among providers is an important first step in overcoming doubts about the usefulness of race and ethnicity data. Providers who do not believe health disparities result from implicit bias are less likely to think collection of race and ethnicity data is important. One solution is to implement implicit bias education throughout the

health care delivery system, including at medical and nursing schools.^{xv} California has enacted a law that requires certain hospitals and centers providing perinatal care to implement evidence-based implicit bias programs.^{xvi} In support of those requirements, the legislation provides the following language related to the connection between implicit bias and health disparities:

...Implicit bias is a key cause that drives health disparities in communities of color. At present, health care providers in California are not required to undergo any implicit bias testing or training. Nor does there exist any system to track the number of incidents where implicit prejudice and implicit stereotypes have led to negative birth and maternal health outcomes...

It is the intent of the Legislature to reduce the effects of implicit bias in pregnancy, childbirth, and postnatal care so that all people are treated with dignity and respect by their health care providers...

Data Collection Training

Implicit bias education may help providers recognize the usefulness of race and ethnicity data in addressing health disparities, but it may not be sufficient to alleviate other provider community concerns unless accompanied by further staff training.

The Health Research Educational Trust (HRET) released its first version of a Disparities Toolkit, aimed at “provid[ing] hospitals, health systems, clinics, and health plans information and resources for systematically collecting race, ethnicity, and primary language data from patients.”^{xvii} HRET recommends

State Data Collection Criteria Scores, from PhRMA's recently concluded study:

Evaluating the Quality, Comprehensiveness, and Availability of Health Disparities Data Reported Publicly by US State Health Departments Between 2015-2020.

State	NIMHD Points**	Linkage to Health Outcomes	Disaggregated Data Collection	Recent Data in Report	Presence of Health Equity /Disparities Report	Total
Nebraska	9 out of 20	1	1	1	1	13
Wisconsin	11 out of 20	1	0	0	1	13
Massachusetts	10 out of 20	0	0	1	1	12
Colorado	9 out of 20	1	0	1	1	12
Indiana	8 out of 20	1	0	1	1	11
D.C.	8 out of 20	1	0	1	1	11
Michigan	8 out of 20	1	0	1	1	11
Connecticut	8 out of 20	1	0	1	0	10
Arizona	8 out of 20	1	0	1	0	10
Rhode Island	7 out of 20	1	0	1	1	10
Washington	8 out of 20	0	0	0	1	10
Virginia	8 out of 20	1	0	0	1	10
Maryland	8 out of 20	0	0	0	1	9
Pennsylvania	7 out of 20	0	0	1	1	9
Vermont	7 out of 20	1	0	0	1	9
California	6 out of 20	1	0	1	1	9

Kentucky	7 out of 20	0	0	1	1	9
Montana	8 out of 20	0	0	1	0	9
Nevada	8 out of 20	0	0	1	0	9
New Jersey	8 out of 20	0	0	1	0	9
New York	7 out of 20	0	0	1	1	9
Illinois	6 out of 20	0	0	1	1	8
Minnesota	5 out of 20	1	0	1	1	8
Oregon	6 out of 20	1	0	1	0	8
Wyoming	6 out of 20	1	0	0	1	8
Florida	7 out of 20	0	0	1	0	8
Alaska	6 out of 20	1	0	1	0	8
Arkansas	6 out of 20	0	0	1	0	7
North Carolina	5 out of 20	0	0	1	1	7
Utah	5 out of 20	0	0	1	1	7
North Dakota	5 out of 20	0	0	1	1	7
New Mexico	6 out of 20	0	0	1	0	7
Mississippi	4 out of 20	0	0	1	1	6
Louisiana	5 out of 20	0	0	1	0	6

South Dakota	5 out of 20	0	0	1	0	6
Texas	4 out of 20	1	0	1	0	6
West Virginia	4 out of 20	1	0	1	0	6
Ohio	5 out of 20	0	0	1	0	6
Hawaii	5 out of 20	0	0	1	0	6
Delaware	4 out of 20	0	0	0	1	5
Oklahoma	4 out of 20	0	0	1	0	5
Missouri	3 out of 20	0	0	1	0	4
South Carolina	4 out of 20	0	0	0	0	4
Georgia	2 out of 20	0	0	1	0	3
Iowa	2 out of 20	0	0	1	0	3
New Hampshire	3 out of 20	0	0	0	0	3
Kansas	1 out of 20	0	0	1	0	2
Tennessee	1 out of 20	0	0	0	0	1
Alabama	1 out of 20	0	0	0	0	1
Maine	1 out of 20	0	0	0	0	1
Idaho	1 out of 20	0	0	0	0	1

*Scores states received for each criterion used to assess the states on their collection of health equity data

**The points for the National Institute on Minority Health and Health Disparities (NIMHD) Minority Health and Health Disparities Research Framework were calculated based on states collection of data within each cross-section of levels and domains in the framework, not each unique data indicator being collected; i.e. poverty, housing, mortality rates, etc.

that staff training should “provide information about why it is important to collect these data, how to collect data, and how to answer questions or address concerns from patients.” Likewise, the Agency for Healthcare Research and Quality (AHRQ) suggests a training approach that incorporates information on the usefulness of data in addressing health needs with information on “how [the data] will be used; how they should be collected; and how concerns of patients, enrollees, and members can be addressed.”^{xviii}

In making these suggestions, AHRQ cited a project by the National Committee for Quality Assurance (NCQA) focused on supporting quality improvements among small physician practices.^{xix} AHRQ reports that at the conclusion of the NCQA project, participants expressed an understanding of the value of race and ethnicity information, and that the project “improved the participants’ understanding of the legal issues related to collecting data from patients on race, ethnicity, and language need.”

Patients

Collecting race and ethnicity information should ultimately benefit communities of color by improving the ability of researchers, providers, and policymakers to develop and implement policies that eliminate disparities in outcomes.

Patient-focused solutions for collecting data are an important consideration for providers. Researchers have found that patients are less hesitant to provide race and ethnicity information when they understand that the information will be used “to monitor care to ensure that all patients get the best care possible.”^{xx}

Community Engagement

To begin overcoming patient concerns and distrust, HRET recommends engaging the patient community at the outset of any data collection initiative. Patient-centered communication is one way to achieve a better partnership with the community, and explaining how information will be used is a critical component of treating the community as an “active and informed” partner.^{xxi} HRET recommends the American Medical Association (AMA) *Ethical Force* program as one resource to improve communication with diverse patient populations. The program includes a set of measures by which health organizations across the delivery system can build trust by assessing and improving communication.

Increased Representation in Provider Communities

Ensuring better representation of communities of color within the provider community is key to addressing patient concerns of systemic racism within the medical system. These concerns



have led to mistrust and apprehension about providing certain information. Many federally funded programs are aimed at developing a more diverse medical community, including the Health Resources and Services Administration's (HRSA) *Health Career Opportunity and Nursing Workforce Diversity Programs* and the *Minority Access to Research Careers and Minority Biomedical Research Support Programs* administered by the National Institutes of Health (NIH).

A discussion paper released by the National Academy of Medicine suggests implementing a new model of student recruitment to reshape the pipeline to careers in medicine.^{xxii} The authors present evidence that early interventions beginning in elementary and middle school are necessary to generate and sustain the forces that lift and retain minority students. The Joint Working Group on Improving Underrepresented Minorities (URMs) Persistence in Science, Technology, Engineering, and Mathematics (STEM) has provided a map to increasing diversity among undergraduates in those fields. It includes recommendations for “creating strategic partnerships, unleashing the power of the curriculum, addressing student resource disparities, and firing students’ creative juices to sustain progress in STEM.”^{xxiii}

BARRIERS TO IMPLEMENTING IDENTIFIED SOLUTIONS

A wealth of information exists on the importance and challenges of collecting data to address health disparities. There is no one solution to these challenges, and many recommendations have been put forth by experts, government agencies, and other stakeholders within the health care delivery system. Despite the work to develop solutions, progress

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has been slow. COVID-19 has highlighted that there is no time to waste in reducing health disparities, and that closing gaps in available data is crucial. Thus, it is imperative that we identify and eliminate barriers that hinder implementation of proposed solutions.

Our research has identified several barriers to the implementation of identified solutions. Like many of the challenges and solutions related to race and ethnicity data collection, these barriers tend to be connected. Additionally, these barriers are not exclusive to federal or state government agencies, nor private entities within health care delivery systems. Stakeholders at all points of engagement are vulnerable to these barriers and should evaluate their organizations and take appropriate corrective action.

Not a Leadership Priority

Improving data collection to measure health disparities has historically not been a leadership priority. This barrier overlays all others and is evidenced by the volume of research and potential solutions put forward on the subjects of health disparities and the need for better

data. There has been a great deal of talk about change and tinkering around the edges of policy, but little concrete and forceful action by people in leadership – private and public. This is also where leaders must face systemic racism head-on. Without the devaluing of Black and Brown lives, it is unlikely that critical gaps in information on race, ethnicity, and health would have been allowed to persist at such scale and that so few solutions identified over the last 35 years would have been implemented or at least piloted in more health systems. Historically, leadership in the public and private sectors has not treated improved data collection to measure health disparities as a priority. A lack of buy-in from highest ranks on data collection and use overlays other barriers and stymies corrective action. Organizations have tinkered around the edges of policy relating to the measurement of health disparities, though these efforts have not been accompanied by concrete and forceful action from the leadership level. Systemic racism underpins this choice

of inaction. The devaluation of Black and Brown lives has permitted these critical gaps in information to persist on a national scale, consequently leaving solutions identified over the past 35 years on a shelf.

Organizational priorities are most often determined by those in leadership positions. Change – especially institutional change – rarely happens without buy-in from the top. If leaders believe the health system is working well or are blind to the need to address racial disparities, then they may not be motivated to make a change or institute new policies that involve data collection.^{xxiv} Even if an organization’s leadership understands the need to address health disparities, misunderstandings may exist regarding how and why race and ethnicity data should be collected. Organizations that have made changes to their technology systems may need to prioritize training, or look beyond their own organizations at the necessity of interoperability as it relates to identifying and eliminating health disparities.

Lack of Funding

Adequate funding is essential to ensuring robust, complete, and accurate data collection. For instance, health surveys must be tailored to certain populations and languages, and quality measures must be implemented to ensure that data are actionable. In states with smaller minority populations, collecting information from a meaningful sample size can be costly because greater outreach efforts are needed.

Funding and resources are essential to adoption of advanced health information technology that can aid race and ethnicity data collection and analysis. The 2009 Health Information Technology for Economic and Clinical



Health (HITECH) Act provided more than \$35B in incentives to encourage hospitals and health care professionals to transition to electronic health records (EHR) and facilitate health information exchange (HIE). Unfortunately, meaningful standards did not exist at the time, and the systems implemented with that funding have not promoted the types of interoperability needed to address health disparities. Health systems are reluctant to invest more money, especially without clear guidance or expectations.

In August of 2020, HHS created the Strengthening the Technical Advancement and Readiness of Public Health Agencies via Health Information Exchange Program (STAR HIE Program) and issued a Notice of Funding Opportunity.^{xxv} The stated purpose of the program and its related funding is to “strengthen and accelerate innovative uses of health information via [HIEs] within states, communities, and regions to support public health agencies’ abilities to advance data-driven prevention of, response to, and recovery from public health events, including disasters and pandemics such as Coronavirus Disease 2019 (COVID-19).” Five awards were granted to various HIEs, totaling \$2.5M and the hope is that these projects will yield positive results and paths forward for others. To make this initiative scalable, though, much more investment will be necessary.

Not a Political Priority

Legislators are unlikely to prioritize the collection and use of race and ethnicity data if they do not understand its importance. Similarly, unused data can cause leaders to withdraw their political or financial support for expending resources on its collection and analysis.



Lack of Collaboration

Failure to engage communities from beginning to end can result in deepening mistrust.^{xxvi} Despite knowledge of the ways in which health research has harmed many communities of color, some agencies or researchers collect data but limit sharing and use, even with the community from which it is collected.^{xxvii} By not sharing and contextualizing findings, those agencies and researchers may reinforce doubts that the work being done is to benefit the community. Additionally, without engagement from the community, researchers and policymakers may not properly tailor health interventions or broad initiatives in ways that are culturally sensitive or seem relevant to the target population.

Without collaboration across departments, agencies, and sectors, it is more difficult to define appropriate categories and share or link data. State and federal government agencies



must rely on private health systems to collect some of the patient data needed to address health disparities. Private entities reporting health data should be able to rely on government agencies to make clear why and how the data will be used. Given the number of junctures where health data runs into significant barriers - despite years of acknowledgment of these barriers by individual agencies, governments, health systems, and technology developers - actionable solutions cannot be implemented until all stakeholders prioritize eliminating disparities and work more closely together to achieve that goal.

Legal and Regulatory Frameworks that Perpetuate Distrust

Race and ethnicity data in health care should be used to understand and eliminate disparities in health outcomes. Many people, though, fear their information or participation could be used to harm them or their communities. For some, those concerns are rooted not just in the systemic racism that underlies many health disparities, but

also legal and regulatory frameworks that reinforce fear of participation in race and ethnicity data collection.

Studies have shown that some level of distrust or concern about providing certain data can be overcome by clear explanations as to why and how the data will be used to close gaps in outcomes.^{xxviii} However, it can be much harder to overcome distrust when it is founded in legal and regulatory frameworks that hinder participation in the health system as a whole. For example, changes to the “public charge” policy regarding potential immigrants to the U.S., first proposed in 2018, have had a chilling effect on participation in health care and public programs by that population.^{xxix} The proposal heavily weighed certain health conditions or reliance on programs like Medicaid and the Children’s Health Insurance Program as negative factors in determining admissibility to the United States. The chilling effects on interactions with the health care system were evident even before the rules became effective and were felt by families and individuals directly affected by the changes, and

people in immigrant communities more broadly.^{xxx} We cannot and should not expect patient participation in data collection efforts if individuals believe there is an actual or perceived legal risk to themselves, their families, or their communities in providing race and ethnicity data.

CONCLUSION

Gaps in health data collection have not caused the health disparities experienced by communities of color - that distinction lies squarely in the systemic racism inherent in nearly every facet of life. However, failure to gather information on race and ethnicity that can improve health outcomes has helped to perpetuate health disparities. The number and variety of proposed solutions indicates that these data gaps are a well-known and studied issue. The lack of progress indicates there are significant roadblocks to action.

...there is no time to spare in implementing solutions to bridge the gap in data collection.

Those roadblocks and barriers are connected to systemic racism and to one another. When leadership fails to prioritize an issue, the likelihood it will receive funding or resources needed to bring stakeholders together to solve problems seems very small. When collaboration is not a priority, policymakers may fail to understand the needs or concerns of the communities most negatively affected.

PhRMA recognizes there is no time to spare in implementing solutions to bridge the gap in data collection. The biopharmaceutical industry strongly believes that diversity, equity, and inclusion are essential to the discovery of new medicines and for access to treatment for people of all ethnic and racial backgrounds. That means taking a more active role through our own actions as an industry as well as supporting public policies that address health disparities, working together with the broader health care sector toward creating a more just and equitable U.S. health care system for everyone.

To date, PhRMA has provided over \$400,000 in COVID-19 Collaborative Actions to Reach Equity (CAREs) Grants. We hope to identify ideas that overcome, work around, or disrupt barriers to action, and that center on communities of color. The third and final paper of this series will highlight some of the initiatives that PhRMA is funding and what others can do to join our efforts.

Want more information on how race and ethnicity data travel through the system? Explore our [Follow the Data factsheet](#) which examines this issue in further detail.

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