

A CALL TO ACTION



A commitment to health equity

Health equity means that all patients have the opportunity to access the healthcare services, supports, and medicines they need to optimize health and well-being, prevent disease, and manage their health conditions.

Longstanding health disparities— preventable differences in health that result from economic, social, or environmental disadvantages¹ among underserved communities— clearly demonstrate that as a society, we have a long way to go before we can achieve health equity. Stresses on health care and emergency preparedness systems during the COVID-19 pandemic exacerbated these

longstanding disparities, highlighting the urgency of addressing factors that drive them.

Health disparities do not only take an undue toll on the lives of disadvantaged communities, but also cost the U.S. health care system and economy more than **\$135 billion** each year.

As our nation continues to navigate and looks forward to the end of this unprecedented public health emergency, PhRMA maintains its commitment to **equity**, and we will continue to advocate for the systematic changes that are needed to improve health outcomes for patients in historically underserved communities.

Health disparities disproportionately affect communities that have systemically experienced greater social or economic obstacles to optimal health based on factors such as...

Race or Ethnicity	Socioeconomic Status	Gender
Age	Mental Health	Cognitive, Sensory, or Physical Disability
Sexual Orientation or Gender Identity	Geographic Location	Any Other Characteristics Historically Linked to Discrimination and Exclusion

Gaps in health data impede the ability to address health disparities

To achieve health equity, critical reforms are needed to ensure equal access to care to facilitate patients' receiving the diagnosis, care plan, and treatment they need. To get there, a strong public health infrastructure is critical to enable an understanding of where gaps in equitable access exist and for whom. A key factor impeding the ability of state and local public health officials, health plans, hospitals,

1. Healthy People 2020. Disparities. Accessed July 2022. <https://www.healthypeople.gov/2020/about/foundation-health-measures/Disparities>

and other stakeholders to routinely address health disparities, including in public health emergencies, is the lack of robust data on the prevalence and drivers of health disparities.

These data gaps result from insufficiently standardized data collection, monitoring, and delivery systems as well as lack of granularity of health outcomes data by social determinants of health factors such as race, ethnicity, and other characteristics that are known to be associated with health disparities (e.g., sexuality and gender identity, education, housing, etc.). For example, **data** from the Centers for Disease Control and Prevention show that as of October 10, 2022 information on race/ethnicity is missing for 25% of people who received at least one dose of the COVID-19 vaccination.

Absent marked improvements in how sociodemographic data are collected, policymakers, healthcare providers, and other stakeholders will remain unable to fully understand, measure, and track health disparities at the level of detail that is needed to achieve health equity in the United States. In addition to perpetuating health disparities, these shortfalls will hinder our nation from not only being fully prepared to face future pandemics, but will hold us back from achieving the modern, technology-driven, and high quality that will best serve today's and tomorrow's patients.

Better data is central to enabling equity in a post-pandemic future

To take steps toward a more resilient and equitable health system, we must improve collection and reporting of health data at the local, state, and tribal levels to identify and address disparities through improved access to medicines and other health care services and supports.

Now is the time to learn from the hard lessons of the pandemic and establish new data systems

that improve our ability as a nation to target factors that have contributed to longstanding health disparities. Improved data can be leveraged not only to mitigate disparities in public health emergencies but can be woven into ongoing efforts that cement health equity as a foundational principle of health care in this country.

Barriers to improving collection and reporting of health equity data

Today, there are **several challenges** that hinder collection of the data needed to systematically address health disparities. These barriers include:

- Outdated **health information technology (HIT) infrastructure** does not allow for interoperability needed to facilitate systematic collection across care settings or synthesized reporting. Improved data collection will not be possible without targeted investments to build adequate HIT systems and research best practices to do so. This includes a properly skilled and representative workforce.
- Insufficient **incentives or requirements** for collection of sociodemographic information in health data systems such as vital records, nationally notifiable disease systems, and hospital discharge data systems.
- There are no **national standards** for collection of sociodemographic data with health data sources such as billing or other administrative records. Additionally, where standards do exist, limited granularity in defined sociodemographic subgroups inhibits the ability identify health disparities across many diverse communities.
- Providers and patients are apprehensive about collection of data on race and ethnicity due to lack of dedicated **education and outreach** efforts that also maintain patient confidentiality and data protection.



PhRMA's Call to Action to Advance Social Determinants of Health Data Collection to Reduce Health Disparities and Advance Health Equity

As part of its ongoing efforts to promote health equity, PhRMA aims to partner with other stakeholders to continue to draw attention to the role that inadequate data collection plays in perpetuating health disparities in the United States and make progress towards solutions to improve data to support health equity. Improving these data will fill longstanding gaps, drive efforts to promote health equity for all Americans, and mitigate the risk of exacerbating disparities in times of national emergency.

We now call on federal, state, and local governments, as well as private sector stakeholders to join us in eliminating barriers that hinder implementation of common-sense policies to fill critical gaps in the availability of data to reduce health disparities. Together, we must take action to identify and drive key solutions to advance health equity data such as:

- **Invest in modernizing HIT infrastructure and identifying best practices** to adequately facilitate development of rapid, nimble, and interoperable data reporting systems.
- **Develop standards in the types of data collected** with adequate granularity to represent diversity across important demographic factors.
- **Implement mechanisms to support and incentivize** standardized data collection across health data systems.
- **Enable community engagement** to ensure diverse and local representation in development of data collection and reporting processes and protocols.
- **Design health plan network adequacy standards** to ensure access to culturally appropriate providers and address the mistrust that is rooted in and sustained by lack of

effective communication, engagement, and collaboration among impacted communities, researchers, policy makers, government agencies, and healthcare providers.

- **Promote provider training** on implicit bias and data collection processes.
- **Establish protocols for public reporting** on disparities in use of health care screenings, medicines, other relevant services, and health outcomes for key diseases by sociodemographic factors.



Beyond data collection, it will be critical to seize opportunities to improve how we harness and interpret data to address health inequities such as:

- 1** Identifying and prioritizing health disparities and gaps in health equity
- 2** Enabling researchers, providers, policy-makers to explore potential solutions
- 3** Testing solutions and sharing best practices

There is no one solution to solving health disparities in the United States, but by working together we can achieve a more just and equitable health system.