America’s Biopharmaceutical Companies Support Systemic, Long-Term Change to Better Meet the Needs of Underserved Communities

We are committed to:

• **Open, honest, and real conversations** about racial equity and what it means to have a culture of inclusion.
• **Expanding opportunities** to work and succeed in our industry.
• **Advancing policy solutions and research** to better address health disparities.
• **Diversifying our business practices** to better invest in underserved communities.
• **Earning trust and addressing systemic issues** that deter underserved communities from participating in clinical trials, so that people who want to participate, can.
A Snapshot of Health Disparities in America
Marginalized Communities Experience Disparities in Health Outcomes Across a Range of Common Conditions

Black people are more likely than white people to die from the leading causes of death in the U.S.¹

Figure recreated from 2018 data displayed in “Racism’s Hidden Toll: In America, how long you live depends on the color of your skin.”¹

Marginalized Communities Experience Disparities in Health Outcomes Across a Range of Common Conditions

American Indian/Alaska Native and Black women experience higher rates of maternal mortality than white women.¹

Disparities in Life Expectancy Were Made Worse by COVID-19

- High COVID-19 mortality among the **Black population** is estimated to have widened the Black-White life expectancy gap.\(^1\) **Disparity in life expectancy widened by 39%**.

- The COVID-19 mortality rate is highest among **American Indian/Alaska Native** populations.\(^2\)

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**DID YOU KNOW?**

Many people of color experienced higher rates of COVID-19 infection, hospitalizations, and mortality while having disparate access to care and treatment.\(^3,4\)

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Inequities in Access to Medicines and Vaccines Contribute to Health Disparities

Disparities in COVID-19 vaccination rates have increased 2x between urban areas and rural areas since April 2021.¹

Figure adapted from “Disparities in COVID-19 Vaccination Coverage Between Urban and Rural Counties — United States, December 14, 2020–January 31, 2022.”¹

Marginalized Communities Are More Likely to Experience Hospitalizations and Mortality that Could Be Avoided with Better Access to Medicines and Other Care

Preventable hospitalizations are **40%** higher among Medicare beneficiaries with chronic disease in rural versus urban areas.\(^1\)

Black patients account for **32%** of preventable deaths by heart disease and stroke.\(^2\)

We could save **$95 billion** over 10 years in health spending with better adherence to medicines among non-white arthritis patients.\(^3\)

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Patient Experiences of Discrimination Exacerbate Health Disparities

Experiences of discrimination in health care settings due to race, ethnicity, and other personal characteristics can result in avoiding, delaying, or disrupting care—and negatively impact trust.¹-³

Share of patients who feel discriminated against due to race, ethnicity, or sexuality when seeking health care⁴

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black Americans</td>
<td>32%</td>
</tr>
<tr>
<td>American Indian/Alaska Natives</td>
<td>23%</td>
</tr>
<tr>
<td>Latino Americans</td>
<td>20%</td>
</tr>
<tr>
<td>Asian Americans</td>
<td>13%</td>
</tr>
<tr>
<td>LGBTQ+ Americans</td>
<td>16%</td>
</tr>
</tbody>
</table>

While Some Progress Has Been Made Towards Reducing Health Inequities . . .

Since publication of the first comprehensive study of racial and ethnic health disparities in the 1985 Heckler Report,¹ there have been steps to close health disparities, including:

10-15% point decrease in the share of uninsured Black and Hispanic adults from 2013 to 2018²

Medicare Part D implementation resulted in 100,400 fewer deaths from diabetes³

800+ Medicines in development for diseases that disproportionately affect racial and ethnic minority communities⁴

. . . There is Still a Long Way to Go.

Addressing Social Determinants of Health, Bias, and Discrimination Throughout a Patient’s Lifetime Will Help Address Health Inequities

Social determinants of health (SDOH) are circumstances in which people live, learn, work, and play.

**Transportation**
Patients with disabilities are **2x more likely** to have inadequate access to transportation than patients without disabilities.¹

**Housing**
28% of LGBTQ+ youth experience homelessness.²

**Environment**
48% of tribal households in Native communities lack access to reliable clean water.³

**Structural Racism**
Racism and discrimination often underlie these determinants of health and drive inequities in health care.

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¹ The Unequal Commute. Urban Institute. 2020. Available at: https://www.urban.org/features/unequal-commute
³ Water Delayed is Water Denied: How Congress has Blocked Access to Water for Native Families. House Committee on Natural Resources. 2016. Available at: https://naturalresources.house.gov/imo/media/doc/House%20Water%20Report_FINAL.pdf
Addressing Social Determinants of Health, Bias, and Discrimination Throughout a Patient’s Lifetime Will Help Address Health Inequities

Social determinants of health (SDOH) are circumstances in which people live, learn, work, and play.

**Income**

Americans in the top 10% of earners make 9 times more than Americans in the bottom 10% of earners.¹

**Nutrition**

21% of Native Hawaiian and Pacific Islander adults face food insecurity.¹

**Digital Divide**

28% of adults living in rural areas lack access to broadband internet access.³

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In Addition to Addressing SDOH, Dismantling Structural Barriers Within the Health Care System Is Necessary to Advance Health Equity

- Bias in Health Care
- Inequities in Access to Screenings and Diagnostics
- Gaps in Access to Medicines
- High Out of Pocket Costs and Other Insurance Barriers
- Gaps in Health Equity Data and Measurement
- Lack of a Diverse Healthcare Workforce
Health Equity Depends on Removing Social and Health System Barriers to Medicine Access Across the Continuum of Care

- **Research and Development**: Bringing innovative medicines to the market
- **Use of Health Data and Tools**: Measuring outcomes and impacts of medicines to inform use and future innovation
- **Access to a Provider and Screenings**: Receiving a diagnosis to be treated
- **Receipt of the Right Prescription**: Prescribing medicine that is best for a patient given their needs and preferences
- **Ability to Fill a Prescription**: Accessing and adhering to medicines that improve and manage outcomes
Inequities in Access to Screenings and Medicines Allow Health Disparities to Persist
Increasing Diverse Representation in Clinical Trials Is Critical to Health Equity

Clinical trial diversity supports equity by:
1. Providing a more holistic and evidence-based understanding of how potential therapies work in diverse populations
2. Granting patients' access to other quality care, including provider visits, screenings, and additional medicines
Increasing Diverse Representation in Clinical Trials Is Critical to Health Equity

Demographic Subgroups

<table>
<thead>
<tr>
<th>Demographic Subgroups*</th>
<th>Black</th>
<th>White</th>
<th>Asian</th>
<th>Hispanic</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Average CT Representation</strong></td>
<td><strong>8%</strong></td>
<td><strong>75%</strong></td>
<td><strong>6%</strong></td>
<td><strong>11%</strong></td>
</tr>
<tr>
<td><strong>US Population</strong></td>
<td><strong>12%</strong></td>
<td><strong>62%</strong></td>
<td><strong>6%</strong></td>
<td><strong>19%</strong></td>
</tr>
<tr>
<td><strong>CT Representation Compared to US Population</strong></td>
<td><strong>-33%</strong></td>
<td><strong>+20%</strong></td>
<td><strong>0%</strong></td>
<td><strong>-42%</strong></td>
</tr>
</tbody>
</table>

*Racial subgroups include Hispanic and non-Hispanic origin populations
**Report on 53 novel drugs approved in 2020, FDA Drug Trial Snapshot
***United States Census Bureau – 2020 Estimates

Systemic Barriers to Clinical Trial Diversity

- Patient Mistrust Grounded in Past Wrongs
- Ongoing Experiences of Discrimination in Health Care
- Economic and Process Burden of Trial Participation
- Limited Diverse Investigators and Staff Running Clinical Trials
- Limited Awareness and Understanding of Clinical Trials
- Limited Access to Trial Sites in Underrepresented Communities
Poor Access to Screenings and Diagnostics Can Delay Treatment and Worsen Outcomes for Underserved Populations

Race and Ethnicity

- **White**
- **Black/African American**
- **Hispanic**
- **American Indian/ Alaska Native**
- **Asian**

Table adapted from Table 7 in AACR Cancer Disparities Progress Report (2020). Available at: https://cancerprogressreport.aacr.org/disparities/chd20-contents/chd20-disparities-in-cancer-screening-for-early-detection/

Poor Access to Screenings and Diagnostics Can Delay Treatment and Worsen Outcomes for Underserved Populations

Fewer than 36% of uninsured patients receive certain recommended cancer screenings.¹

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Screening Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast Cancer</td>
<td>35.3%</td>
</tr>
<tr>
<td>Colorectal Cancer</td>
<td>25.1%</td>
</tr>
<tr>
<td>Prostate Cancer</td>
<td>10.2%</td>
</tr>
</tbody>
</table>

Table adapted from Table 7 in AACR Cancer Disparities Progress Report.²

Risk of Mortality, Late-Stage Diagnosis, and Lower Quality Care Is Higher Among Cancer Patients of Color

Mortality rates for colorectal cancer are

44% higher for Black males than white males.¹

American Indian/Alaska Native women are approximately

31% more likely to be diagnosed with breast cancer at a later stage than white women.²

Hispanic women have up to a

30% higher risk of receiving non-guideline concordant treatment for breast cancer than white women.³

DID YOU KNOW?
Asian American and Pacific Islander women are 2.5x more likely to die from stomach cancer compared to white women.⁴

Pharmacy Deserts Can Limit Access to Medicines

One-third of highly populated urban neighborhoods have poor access to a nearby pharmacy either due to distance or lack of transportation.¹

In Chicago, 54% of predominantly Black communities are pharmacy deserts* while less than 5% of predominantly white communities are pharmacy deserts.³

*In this research, a pharmacy desert is defined as a community that has both low income and low access. In this definition, low access is defined as having more than 33% of its population live more than a mile from a pharmacy or has poor access to a vehicle and live more than half a mile from a pharmacy.


Implicit Bias Contributes to Inequity in Patients’ Access to Medicines and Health Care Services

Implicit (subconscious) bias refers to the “attitudes or stereotypes that affect our understanding, actions, and decisions in an unconscious manner.”

Implicit bias results in:

1. Patient Distrust in Medical Care
2. Disparate Treatment Recommendations
3. Lower Quality of Care and Undertreatment

1. Understanding Implicit Bias. The Kirwan Institute for the Study of Race and Ethnicity. 2012. Available at: https://kirwaninstitute.osu.edu/article/understanding-implicit-bias
Stark Disparities Exist in Access to Innovative Medicines

All patients can potentially benefit from newer classes of medicines, but marginalized populations face significant access barriers.

American Indian and Alaska Native patients are 49% less likely to initiate newer classes of diabetes medicines than white patients due to provider treatment patterns, insurance, and/or patient preference.¹

Black patients are 2x less likely to receive CAR-T treatment as compared to white, Asian, and Hispanic patients.²

Black patients are 33% less likely to receive immunotherapy for metastatic melanoma compared to white patients.³

The LGBTQ+ Community Faces Disparities in Medicine Use

A disproportionate share of adults who identify as lesbian, gay, bisexual, transgender, or queer often delay or do not fill prescribed medicines, partly due to lack of insurance coverage.¹

Percent of adults in California who delayed or didn’t get prescription medications by gender identity and sexual orientation

Lower Medication Adherence Among Disadvantaged Communities Hinders Health Equity

Adherence to select, recommended chronic disease medicines is 10 -12% lower among privately insured Black and Hispanic patients compared to white patients.¹

<table>
<thead>
<tr>
<th>Race and Ethnicity</th>
<th>Oral Diabetes Medicines</th>
<th>Hypertension Medicines</th>
<th>High Cholesterol Medicines</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>74.3%</td>
<td>80.2%</td>
<td>77.0%</td>
</tr>
<tr>
<td>Asian</td>
<td>68.5%</td>
<td>72.5%</td>
<td>72.9%</td>
</tr>
<tr>
<td>Black</td>
<td>69.4%</td>
<td>72.3%</td>
<td>68.4%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>68.4%</td>
<td>77.5%</td>
<td>72.9%</td>
</tr>
</tbody>
</table>

Table from, Racial and ethnic disparities in medication adherence among privately insured patients in the United States.¹

*PDC: Proportion of Days Covered

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Table from, Racial and ethnic disparities in medication adherence among privately insured patients in the United States.¹

¹PDC: Proportion of Days Covered

Even for Insured Patients, High Out-of-Pocket Costs Can Be a Hurdle to Medication Access

Rate of Abandonment of Brand Medicines with Out-of-Pocket Costs of $125 or More Among Commercially Insured Patients, 2020

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Annual Income</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>White</td>
</tr>
<tr>
<td></td>
<td>More than $100,000</td>
</tr>
<tr>
<td></td>
<td>Less than $100,000</td>
</tr>
<tr>
<td>Black</td>
<td>White</td>
</tr>
<tr>
<td></td>
<td>More than $100,000</td>
</tr>
<tr>
<td></td>
<td>Less than $100,000</td>
</tr>
</tbody>
</table>

+6% White vs. Black
+9% More than $100,000 vs. Less than $100,000

Increasing Pre-Deductible Coverage Can Improve Access for Low-Income Patients

- Patients in a high deductible health plan (HDHP) pay **2.4 to 3.7 times less** out of pocket for insulin when it is covered pre-deductible.\(^1\)
- **81%** of employers surveyed would cover more services before the deductible if allowed by law.\(^2\)
- Black, Hispanic, and low-income enrollees are **less likely** than white and high-income enrollees to have a health savings account.\(^3\)

### Average Out-of-Pocket Spending on Insulin Among Patients in HDHPs, 2018\(^1\)

<table>
<thead>
<tr>
<th></th>
<th>Did not meet deductible</th>
<th>Did meet the deductible</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients in HDHPs that Subject Insulin to Deductible</td>
<td>$351 \times 2.4 = $842</td>
<td>$1,197</td>
</tr>
</tbody>
</table>

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Sharing Manufacturer Rebates Directly with Patients Is One Way to Improve Access, Especially for Black and Hispanic Communities

Sharing rebates directly with commercially-insured patients could reduce:\n
- Total health care costs by $1,000 per person annually or $8 billion over 10 years
- Patient spending by $1.5 billion over 10 years
- Mortality by 700 deaths annually

Sharing manufacturer rebates directly with commercially-insured patients can result in a 9% average improvement in adherence\(^1\)

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A pneumococcal vaccine given to older adults is estimated to be more cost effective for the Black population as compared to the general population due to disparities in childhood vaccination and underlying health conditions. If coverage were determined based on value to an average patient, Black patients could be denied a treatment that is high value for them.

Value Assessment Should Represent Diverse Populations, Their Preferences, and Their Experiences

Less than 60% of evidence used to measure quality-adjusted life years (QALYs) for cost-effectiveness analyses reports information on race and less than 15% of evidence reports ethnicity, disability or employment status.¹

*Study represents a sample of articles from two journals published in 2019 – 2021.


Failure to Account for Health Disparities in Value Assessment Can Lead to Bias Against Marginalized Populations

“Structural deficiencies in the models that underlie value assessment have perpetuated health inequities. Communities of color and other groups are generally not represented in the data used to make health care decisions, routinely disadvantaging them.”

-Innovation and Value Initiative

According to the QALY, the value of a life-saving treatment is assumed to benefit Black patients up to 10% less than white patients.


Gaps in Health Data Collection Inhibit Our Ability to Identify and Address Health Disparities

Barriers to better health equity data\(^1\):

- Types of data collected are not standardized or granular
- Data collection systems are outdated and impede interoperability
- Apprehension about data collection is a challenge

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**DID YOU KNOW?**

Aggregating data on different Asian American subgroups under one “Asian” label masks significant disparities in access to care and health outcomes among Asian and Pacific Islander ethnicities.\(^2\)

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Investing in Better Health Data Can Bridge Health Care Gaps and Inform Health Equity Solutions

Stakeholders across the health care system are calling for more diverse representation in health data and concerted efforts to:

- **Incentivize** race, ethnicity, language, and other demographic data collection
- Leverage existing data sources to **systematically and regularly** report on health disparities
- Partner with communities to identify ways to collect and use **health equity data**
- **Safeguard patient privacy** and ensure appropriate use of data
PhRMA’s Commitment to Building a More Equitable Health Care System for All
The PhRMA Equity Initiative Aims to Build Necessary, Positive, and Long-term Systemic Change

Clinical Trial Diversity
Support community-based clinical trial infrastructure so patients who want to participate can

Health Equity
Work towards addressing health system and social factors that impact health inequities

Talent
Support growth in a diverse industry talent pool
PhRMA Principles on Clinical Trial Diversity Amplify Industry Commitment

Building Trust and Acknowledging Past Wrongs to Encourage Clinical Trial Participation

Reducing Barriers to Clinical Trial Access

Using Real-World Data to Inform Medicine Uses for Diverse Populations Beyond Product Approval

Enhancing Information About Diversity and Inclusion in Clinical Trial Participation
Supporting Creation of a Community-based Infrastructure

Disparate sites at varying levels of readiness / community connectiveness

Create an Infrastructure that Provides...

- A network
- Communications
- Community Relationships
- Ongoing site training
- Sustainable support
- Standardized platforms / metrics

A sustainable community-based infrastructure supporting multiple touchpoints / sites dedicated to CT diversity
Equitable Breakthroughs in Medicine Development is an industry-wide, community-based effort focused on supporting sites and patients in underrepresented communities to enhance clinical trial diversity in a sustainable way.

Led by:

EQUITABLE BREAKTHROUGHS IN MEDICINE DEVELOPMENT™

Morehouse School of Medicine
Yale School of Medicine
RCMI Coordinating Center
Vanderbilt University Medical Center

Funded by a grant from PhRMA
Goals

1. Show proof of concept for a comprehensive, collaborative **network of sustainable, connected, community-based sites** supporting clinical trial diversity in underserved communities.

2. Partner with trusted messengers and community leaders to raise education, awareness, and support for clinical trial participation.

3. Provide the resources and technical support for local sites to be successful, sustainable, and to thrive.

4. Build training opportunities and mentorship for investigators and staff.
PhRMA is Undertaking Efforts to Advance Health Equity in Partnership with Community Organizations and Other Partners

- **Support universities and community organizations** to address social determinants of health that impact inequities leading to underdiagnosis and undertreatment.

- **Promote multi-stakeholder partnerships** to drive improved collection and reporting of health data to measure equities in use of medicine and screenings.

- **Advance better health technology assessment** that helps to address health equity by capturing and addressing outcomes that matter to diverse populations.
Collaborative Actions to Reach Equity (CAREs) Grant Program

The PhRMA CAREs grant program supports community-centered solutions to address health inequities, particularly access to medicines, through partnerships with community-led organizations.

CAREs grant funding supports local and national research activities to drive meaningful on-the-ground change to advance health equity through potential best practices and scalable, practical interventions.
The PhRMA CAREs Grant Program has Awarded Nearly $500,000 to Community Efforts to Advance Health Equity

Advancing access through community-driven potential best practices

Using Community Health Workers to Prevent COVID-19 in Low-Income Black Communities
**Sisters in Birth, Inc.** Madison, Hinds, Rankin County MS

Examining Impact of Implicit Bias to Prevent Differential Outcomes in COVID-19 and Other Conditions by Race
**Xavier University**, Louisiana American Academy of Pediatrics

Addressing Racial Disparities in Medication Utilization and Adherence
**Florida A&M University and University of Florida**, Tallahassee and Gainesville, FL

Breaking Down Barriers to the Uptake of COVID-19 Vaccines by Local African and African American Communities in Portland
**Bridge-Pamoja**, Portland, OR

Addressing Underlying Hypertension, Medication Adherence in Patients at High Risk of Contracting and/or Experiencing Complications from COVID-19
**AltaMed Institute for Health Equity**, American Heart Association and California State University

Supporting Access to COVID-19 Vaccines among Teens, Young Adults, and American Indian/Alaska Native Communities
**National Association of Councils on Developmental Disabilities**

PhRMA is helping to bridge the gap to advance health equity
Building a Diverse Talent Pipeline to Industry by Connecting Emerging Talent with Leading Biopharmaceutical Companies that Will Better Serve Patients

• In 2022, PhRMA launched a new LinkedIn Community connecting diverse emerging talent and member companies throughout the year.

• In 2021, Pathways to Success in Biopharma brought together undergraduate and graduate students, postdoctoral trainees, faculty, member companies, and other community partners for a multi-day summit.
The Biopharmaceutical Industry Is Committed to Growing Tomorrow’s STEM Workforce in the United States

- The biopharmaceutical industry has a sustained commitment to enhancing the country’s STEM education and diverse talent pipeline by **inspiring and developing the next generation of STEM professionals**.

- Broadening participation in STEM fields to groups historically underrepresented is critical to strengthening America’s innovation economy and **cultivating economy prosperity**.
Progress Built on Commitment

Follow Our Progress on phrma.org/equity