

#### Statement from PhRMA Board Chair, Ramona Sequeira



"Equitable access to quality medicines and care will meaningfully transform the lives of millions of Americans – particularly those in our most vulnerable and underserved communities. By collaborating across the public and private sectors, we can build capacity, identify and remove barriers and leverage technology to enable health care systems that work for all, not just some."



Chair, PhRMA Board of Directors and President of Takeda, Global Portfolio Division



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

#### We are committed to:

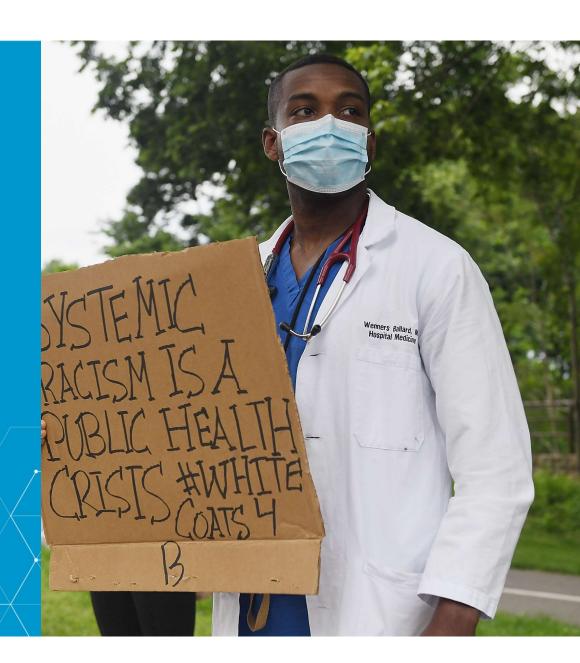
- Open, honest, and real conversations about racial equity and what it means to have a culture of inclusion.
- Expanding opportunities to work and succeed in our industry.
- Advancing policy solutions and research to better address health disparities.
- Diversifying our business practices to better invest 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.

SYSTEMIC
RACISM IS AS
REAL AS ANY
DISEASE.
OUR INDUSTRY IS
NOT IMMUNE.



Section 1

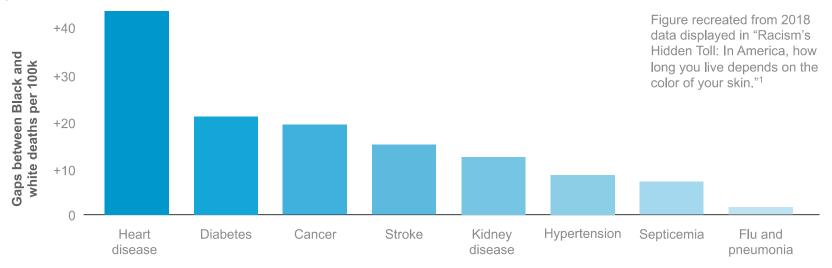
A Snapshot of Health Disparities in America





#### 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.<sup>1</sup>



Causes of death with a higher Black death rate

<sup>1. &</sup>quot;Racism's Hidden Toll: In America, how long you live depends on the color of your skin." The New York Times, 2020, https://www.nytimes.com/interactive/2020/08/11/opinion/us-coronavirus-black-mortality.html

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



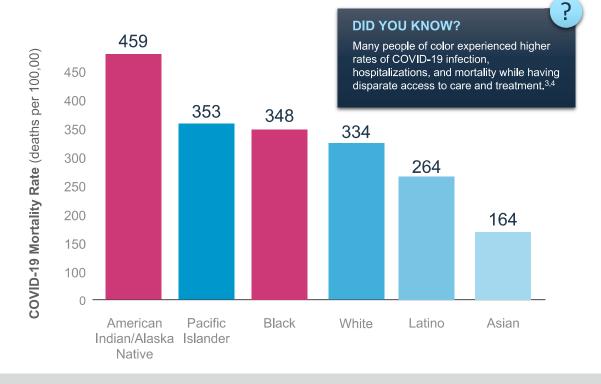
American Indian/Alaska Native and Black women experience **higher** rates of maternal mortality than white women. <sup>1</sup>



<sup>1.</sup> Pregnancy Mortality Surveillance System. Centers for Disease Control and Prevention. https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm. Accessed: April 2022.

#### 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.<sup>1</sup> Disparity in life expectancy widened by 39%.
- The COVID-19 mortality rate is highest among American Indian/Alaska Native populations.<sup>2</sup>



- 1. Andrasfay T, Goldman N. Reductions in 2020 US life expectancy due to COVID-19 and the disproportionate impact on the Black and Latino populations. Preprint. medRxiv. 2020;2020.07.12.20148387. Published 2020 Oct 15. doi:10.1101/2020.07.12.20148387
- 2. The Color of Coronavirus: COVID-19 Deaths by Race and Ethnicity in the U.S. APM Research Lab. https://www.apmresearchlab.org/covid/deaths-by-race. Accessed July 2022
- 3. Rubin-Miller L, Alban C, Artiga S, Sullivan S. COVID-19 Racial Disparities in Testing, Infection, Hospitalization, and Death: Analysis of Epic Patient Data. Kaiser Family Foundation. Sept 2020. https://www.kff.org/coronavirus-covid-19/issue-brief/covid-19-racial-disparities-testing-infection-hospitalization-death-analysis-epic-patient-data/
- 4. Wiltz JL, Feehan AK, Molinari NM, et al. Racial and Ethnic Disparities in Receipt of Medications for Treatment of COVID-19 United States, March 2020–August 2021. MMWR Morb Mortal Wkly Rep 2022;71:96–102. DOI: http://dx.doi.org/10.15585/mmwr.mm7103e1

### 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.<sup>1</sup>



<sup>1.</sup> Saelee R, Zell E, Murthy BP, et al. Disparities in COVID-19 Vaccination Coverage Between Urban and Rural Counties — United States, December 14, 2020—January 31, 2022. MMWR Morb Mortal Wkly Rep 2022;71:335—340. DOI: http://dx.doi.org/10.15585/mmwr.mm7109a2.

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.<sup>1</sup>



Black patients account for

32%

of preventable deaths by heart disease and stroke.<sup>2</sup>



We could save

\$95 billion

over 10 years in health spending with better adherence to medicines among non-white arthritis patients.<sup>3</sup>

<sup>1.</sup> Johnston KJ, Wen H, Joynt Maddox KE. Lack of Access to Specialists Associated with Mortality and Preventable Hospitalizations of Rural Medicare Beneficiaries. *Health Affairs*. 2019; 38(12). https://doi.org/10.1377/hlthaff.2019.00838

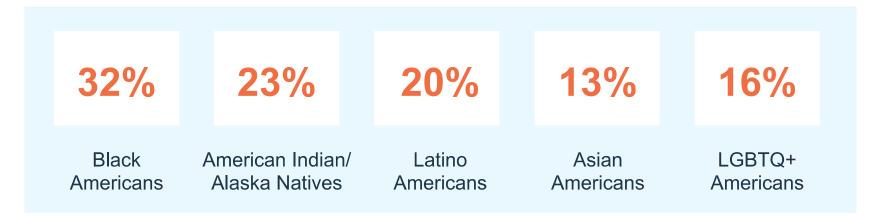
<sup>2.</sup> Khan MS, Kumar P, Sreenivasan J, et al. Preventable Deaths From Heart Disease and Stroke Among Racial and Ethnic Minorities in the United States. *Circ Cardiovasc Qual Outcomes*, 2021;14(7):e007835. doi:10.1161/CIRCOUTCOMES.121.007835

<sup>3.</sup> Advancing Health Equity Would Save \$3.8Trillion. Partnership to Fight Chronic Disease. Sept 2022. Available at: https://www.fightchronicdisease.org/sites/default/files/PFCD%20-%20Health%20Equity%20Fact%20Sheet%20%28National%29.pdf

#### 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.<sup>1-3</sup>

Share of patients who feel discriminated against due to race, ethnicity, or sexuality when seeking health care<sup>4</sup>



<sup>1.</sup> Institute of Medicine (US) Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, Smedley BD, Stith AY, Nelson AR, eds. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington (DC): National Academies Press (US); 2003. 4, Assessing Potential Sources of Racial and Ethnic Disparities in Care: The Clinical Encounter. Available from: https://www.ncbi.nlm.nih.gov/books/NBK220340/

<sup>2.</sup> Rhee TG, Marottoli RA, Van Ness PH, Levy BR. Impact of Perceived Racism on Healthcare Access Among Older Minority Adults. Am J Prev Med. 2019;56(4):580-585. doi:10.1016/j.amepre.2018.10.010

<sup>3.</sup> Skopec L, Gonzalez D, Kenney G. Most Adults Who Feel Treated or Judged Unfairly by Health Care Providers Report Adverse Consequences. Urban Institute. 2021. Available at: https://www.urban.org/sites/default/files/publication/104564/most-adults-who-feel-treated-or-judged-unfairly-by-health-care-providers-report-adverse-consequences 0.pdf

<sup>4.</sup> Discrimination in America: Final Summary, Robert Wood Johnson Foundation, 2018, Available at: https://www.rwif.org/en/library/research/2017/10/discrimination-in-america--experiences-and-views.html

### 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,<sup>1</sup> 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 2018<sup>2</sup>



Medicare Part D implementation resulted in

100,400

fewer deaths from diabetes<sup>3</sup>



+008

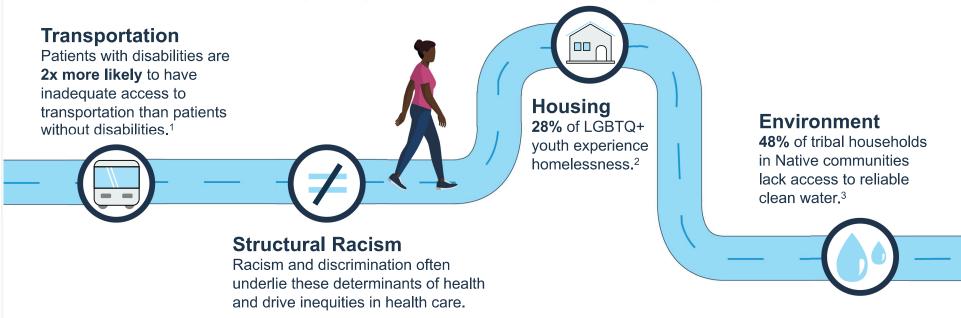
Medicines in development for diseases that disproportionately affect racial and ethnic minority communities<sup>4</sup>

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

- 1. Report of the Secretary's Task Force on Black & Minority Health. U.S. Department of Health and Human Services. 1985. https://collections.nlm.nih.gov/catalog/nlm:nlmuid-8602912-mvset
- 2. The Commonwealth Fund. Affordable Care Act Has Narrowed Racial and Ethnic Gaps in Access to Health Care, But Progress Has Stalled. 2020. https://www.commonwealthfund.org/press-release/2020/new-report-affordable-care-act-has-narrowed-racial-and-ethnic-gaps-access-health
- 3. Semilla AP, Chen F, Dall TM. Reductions in mortality among Medicare beneficiaries following the implementation of Medicare Part D. Am J Manag Care. 2015;21(9 Suppl):s165-s171. https://pubmed.ncbi.nlm.nih.gov/26295437
- 4. Medicines in Development for Health Equity 2021 Report. PhRMA. 2021. Available at: https://phrma.org/resource-center/Topics/Medicines-in-Development/Medicines-in-Development-for-Health-Equity-2021-Report

# 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.



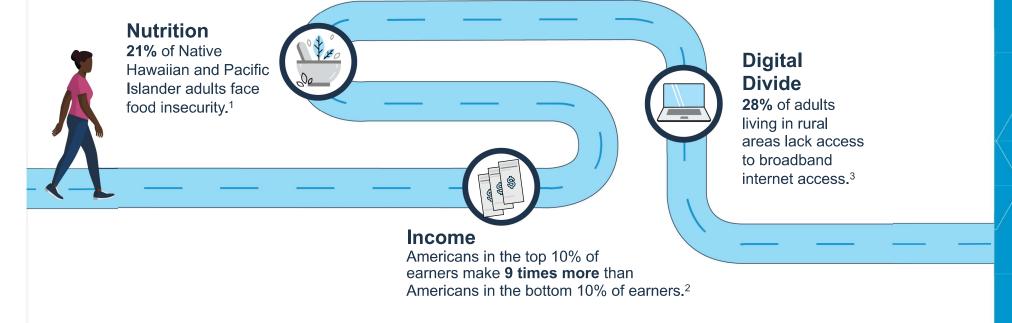
<sup>.</sup> The Unequal Commute. Urban Institute. 2020. Available at: https://www.urban.org/features/unequal-commute

<sup>.</sup> Homelessness and Housing Instability Among LGBTQ Youth. The Trevor Project. 2022. Available at: https://www.thetrevorproject.org/research-briefs/homelessness-and-housing-instability-among-lgbtq-youth-feb-2022/

<sup>3.</sup> 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.pd

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

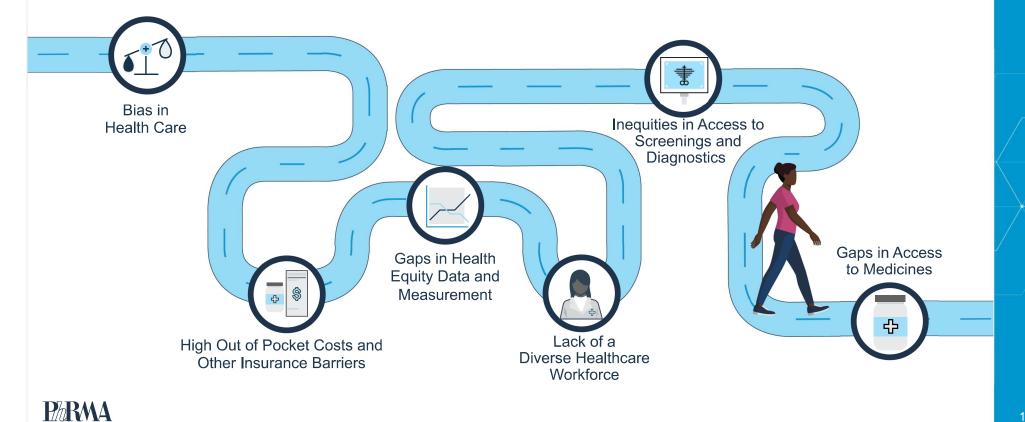
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Income Inequality in the U.S. is Rising Most Rapidly Among Asians. Pew Research Center. 2018. Available at: https://www.pewresearch.org/social-trends/2018/07/12/income-inequality-in-the-u-s-is-rising-most-rapidly-among-asians/
 Long CR, Rowland B, McElfish PA, Ayers BL, Narcisse MR. Food Security Status of Native Hawaiians and Pacific Islanders in the US: Analysis of a National Survey. *J Nutr Educ Behav*. 2020;52(8):788-795. doi:10.1016/j.jneb.2020.01.00

<sup>3.</sup> Vogels E. Some digital divides persist between rural, urban and suburban America. Pew Research Center. 2021. Available at: https://www.pewresearch.org/fact-tank/2021/08/19/some-digital-divides-persist-between-rural-urban-and-suburban-america/

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



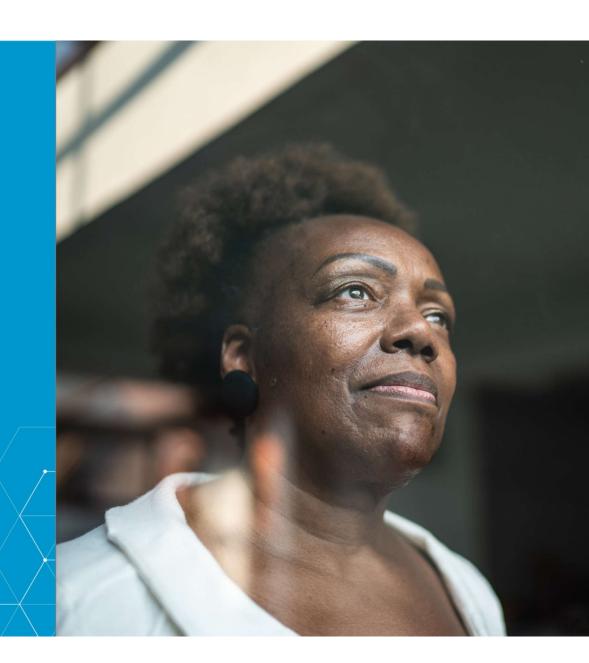
#### Health Equity Depends on Removing Social and Health System Barriers to Medicine Access Across the Continuum of Care



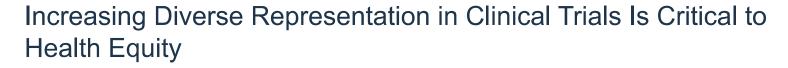


Section 2

Inequities in Access to Screenings and Medicines Allow Health Disparities to Persist







#### Clinical trial diversity supports equity by:

- Providing a more holistic and evidencebased understanding of how potential therapies work in diverse populations
- Granting patients<sup>2</sup> access to other quality care, including provider visits, screenings, and additional medicines







#### Demographic Subgroups

\*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

Demographic Subgroups*	Black	White	Asian	Hispanic
Average CT Representation <sup>1**</sup>	8%	75%	6%	11%
US Population <sup>2***</sup>	12%	62%	6%	19%
CT Representation Compared to US Population	-33%	+20%	0%	<b>-42</b> %

<sup>1. 2020</sup> Drug Trials Snapshots Summary Report. U.S. Food & Drug Administration, 2021. Available at: https://www.fda.gov/media/145718/download

<sup>2.</sup> Jones N, Marks R, Ramirez R, Rios-Vargas M. 2020 Census Illuminates Racial and Ethnic Composition of the Country. United States Census Bureau. 2021. Available at: https://www.census.gov/library/stories/2021/08/improved-race-ethnicity-measures-reveal-united-states-population-much-more-multiracial.html

#### 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



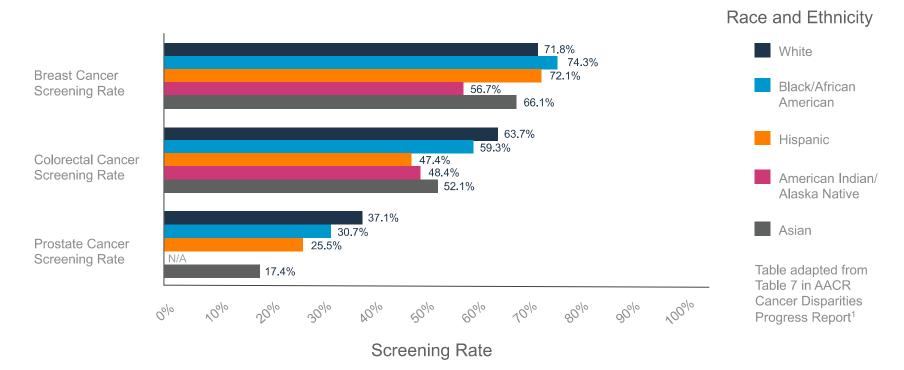
Limited Awareness and Understanding of Clinical Trials



Limited Access to Trial Sites in Underrepresented Communities



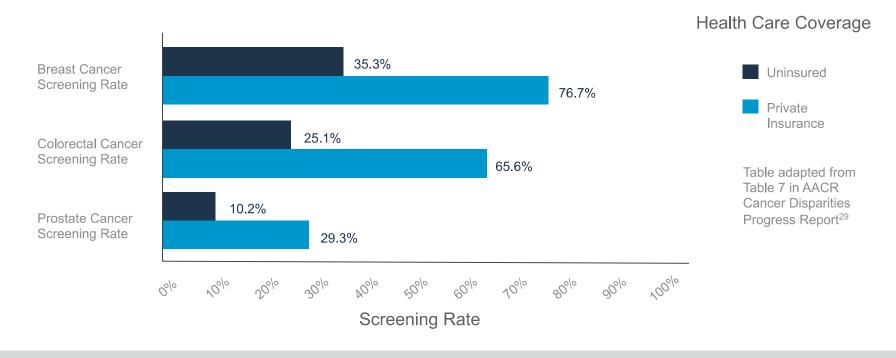
# Poor Access to Screenings and Diagnostics Can Delay Treatment and Worsen Outcomes for Underserved Populations



<sup>1.</sup> AACR Cancer Disparities Progress Report 2020. American Association for Cancer Research, 2020. Table 7.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<sup>1</sup>



<sup>1.</sup> AACR Cancer Disparities Progress Report 2020. American Association for Cancer Research, 2020. Table 7.Available at: https://cancerprogressreport.aacr.org/disparities/chd20-contents/chd20-disparities-in-cancer-screening-for-early-detection/

### 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.<sup>1</sup>

American Indian/Alaska Native women are approximately

31%

more likely to be diagnosed with breast cancer at a later stage than white women.<sup>2</sup>

Hispanic women have up to a

30%

higher risk of receiving non-guideline concordant treatment for breast cancer than white women.<sup>3</sup>

#### **DID YOU KNOW?**

Asian American and Pacific Islander women are 2.5x more likely to die from stomach cancer compared to white women.<sup>4</sup>

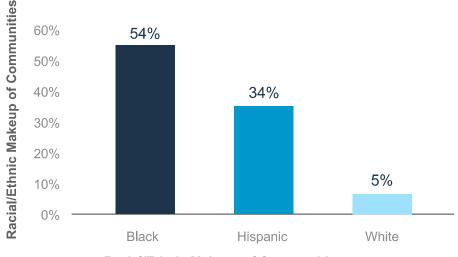
- 1. Cancer Stat Facts: Colorectal Cancer. National Cancer Institute. Surveillance, Epidemiology, and End Results Program. 2022. https://seer.cancer.gov/statfacts/html/colorect.html
- 2. Racial and Ethnic Disparities. American Lung Association. 2021. Available at: https://www.lung.org/research/state-of-lung-cancer/racial-and-ethnic-disparities
- 3. Ko NY, Hong S, Winn RA, Calip GS. Association of Insurance Status and Racial Disparities With the Detection of Early-Stage Breast Cancer. JAMA Oncol. 2020;6(3):385-392. doi:10.1001/jamaoncol.2019.5672
- 4. Cancer and Asian Americans. Office of Minority Health. https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=46. Accessed: June 2022.



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

In over **40%** of U.S. counties, people are required to **drive at least 15 minutes to reach a nearby pharmacy**. Rural states such as Kansas, Montana, South Dakota, and Nebraska have the largest number of counties with pharmacy deserts.<sup>2</sup>

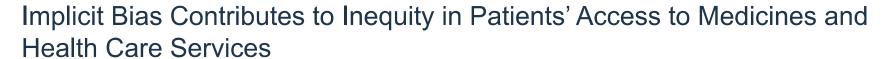
In Chicago, 54% of predominantly Black communities are pharmacy deserts\* while less than 5% of predominantly white communities are pharmacy deserts.<sup>3</sup>



**Racial/Ethnic Makeup of Communities** 

\*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.

- 1. Guadamuz JS, Wilder JR, Mouslim MC, Zenk SN, Alexander GC, Qato DM. Fewer Pharmacies In Black And Hispanic/Latino Neighborhoods Compared With White Or Diverse Neighborhoods, 2007-15. Health Aff (Millwood). 2021;40(5):802-811. doi:10.1377/hlthaff.2020.01699
- 2. Qato DM, Daviglus ML, Wilder J, Lee T, Qato D, Lambert B. 'Pharmacy Deserts' Are Prevalent In Chicago's Predominantly Minority Communities, Raising Medication Access Concerns. *Health Affairs*. 2014; 33 (11). https://doi.org/10.1377/hlthaff.2013.1397
- 3. Nguyen A, Van Meijgaard J, Kim S, Marsh T. Mapping Healthcare Deserts. GoodRx Health. 2021. Available at: https://assets.ctfassets.net/4f3rgqwzdznj/1XSI43I40KXMQiJUtl0ilq/ad0070ad4534f9b5776bc2c41091c321/GoodRx\_Healthcare\_Deserts\_White\_Paper.pdf



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

#### Implicit bias results in:



Patient Distrust in Medical Care<sup>2</sup>



Disparate Treatment Recommendations<sup>3</sup>



Lower Quality of Care and Undertreatment<sup>4,5</sup>

- 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
- 2. Williams JC. Black Americans don't trust our healthcare system here's why. *The Hill*. 2017. Available at: https://thehill.com/blogs/pundits-blog/healthcare/347780-black-americans-dont-have-trust-in-our-healthcare-system/
- 3. Green AR, Carney DR, Pallin DJ, et al. Implicit bias among physicians and its prediction of thrombolysis decisions for black and white patients. J Gen Intern Med. 2007;22(9):1231-1238. doi:10.1007/s11606-007-0258-5
- 4. Penner LA, Dovidio JF, Gonzalez R, et al. The Effects of Oncologist Implicit Racial Bias in Racially Discordant Oncology Interactions. J Clin Oncol. 2016;34(24):2874-2880. doi:10.1200/JCO.2015.66.3658
- 5. Fiscella K, Epstein RM, Griggs JJ, Marshall MM, Shields CG. Is physician implicit bias associated with differences in care by patient race for metastatic cancer-related pain?. *PLoS One*. 2021;16(10):e0257794. Published 2021 Oct 27. doi:10.1371/journal.pone.0257794



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.<sup>1</sup> Black patients are **ZX**less likely to receive CAR-T treatment as compared to white, Asian, and

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

Hispanic patients.<sup>2</sup>

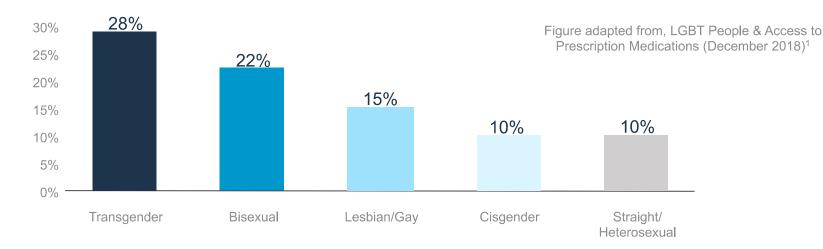
<sup>1.</sup> Elhussein A, Anderson A, Bancks MP, et al. Racial/ethnic and socioeconomic disparities in the use of newer diabetes medications in the Look AHEAD study. *Lancet Reg Health Am.* 2022;6:100111. doi:10.1016/j.lana.2021.100111

<sup>2.</sup> Ahmed N, Shahzad M, Shippey E, et al. Socioeconomic and Racial Disparity in Chimeric antigen receptor T cell (CAR T) Therapy Access [published online ahead of print, 2022 Apr 13]. *Transplant Cell Ther*. 2022;\$2666-6367(22)01224-6. doi:10.1016/j.jtct.2022.04.008

<sup>3.</sup> Haque W, Verma V, Butler EB, Teh BS. Racial and Socioeconomic Disparities in the Delivery of Immunotherapy for Metastatic Melanoma in the United States. *J Immunother*. 2019;42(6):228-235. doi:10.1097/CJI.0000000000000264



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.<sup>1</sup>

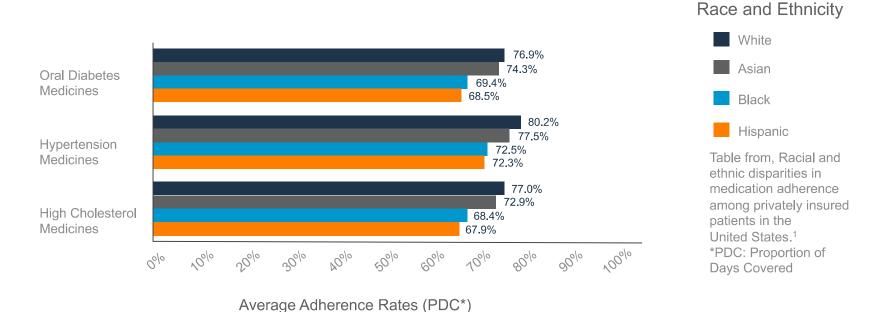


Percent of adults in California who delayed or didn't get prescription medications by gender identity and sexual orientation

1. Sears B, Conron KJ. LGBT People & Access to Prescription Medications. University of California at Los Angeles School of Law. Available at: https://williamsinstitute.law.ucla.edu/publications/lgbt-access-prescription-meds/. Accessed July 21, 2021.

# Lower Medication Adherence Among Disadvantaged Communities Hinders Health Equity

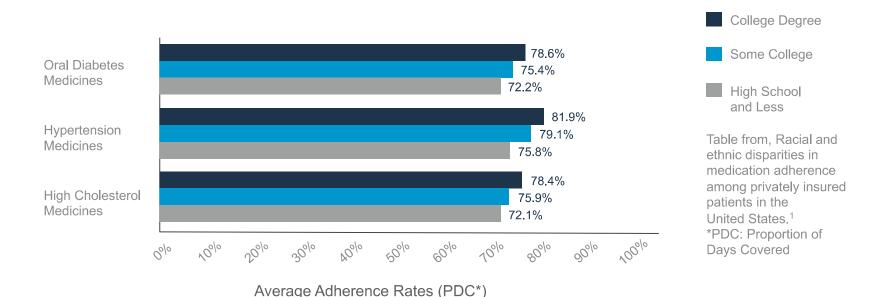
Adherence to select, recommended chronic disease medicines is 10 -12% lower among privately insured Black and Hispanic patients compared to white patients.



1. Xie Z, St Clair P, Goldman DP, Joyce G. Racial and ethnic disparities in medication adherence among privately insured patients in the United States. *PLoS One*. 2019;14(2):e0212117. Published 2019 Feb 14. doi:10.1371/journal.pone.0212117

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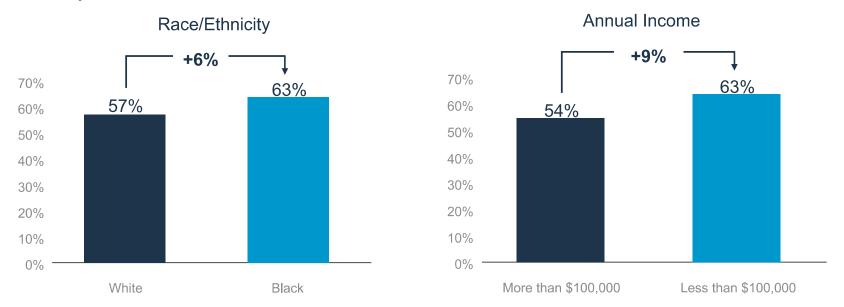
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#### Even for Insured Patients, High Out-of-Pocket Costs Can Be a Hurdle to Medication Access

Rate of Abandonment of Brand Medicines with Out-of-Pocket Costs of \$125 or More Among Commercially Insured Patients, 2020<sup>1</sup>



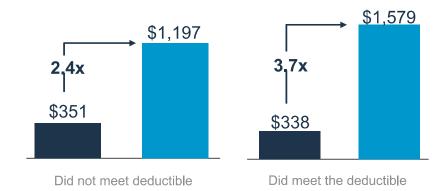
<sup>1.</sup> Understanding Medicine Abandonment as a Barrier to Health Equity. PhRMA. 2022. https://phrma.org/Equity/Understanding-Medicine-Abandonment-as-a-Barrier-to-Health-Equity

#### 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.<sup>1</sup>
- 81% of employers surveyed would cover more services before the deductible if allowed by law.<sup>2</sup>
- Black, Hispanic, and low-income enrollees are less likely than white and high-income enrollees to have a health savings account.<sup>3</sup>



- Patients in HDHPs that Subject Insulin to Deductible
- Patients in HDHPs with First Dollar Coverage for Insulin



- 1. Out-of-Pocket Spending for HDHP Patients Taking Insulin & Impact of Shifting to First Dollar Coverage. Xcenda. 2020. Available at: https://www.xcenda.com/-/media/assets/xcenda/english/content-assets/white-papers-issue-briefs-studies-pdf/xcenda\_diabetes\_hdhp\_claims\_analysis\_report\_2020-10-1\_final.pdf?la=en&hash=6E88FC4F9B414CB3B33D91D17D0575AB918E2A5B
- 2. Fronstin P, Fendrick M. Employer Uptake of Pre-Deductible Coverage for Preventative Services in HSA-Eligible Health Plans. EBRI Issue Brief. 2021; no. 542.https://www.ebri.org/docs/default-source/ebri-issue-brief/ebri\_ib\_542\_hsaemployersur-14oct21.pdf?sfvrsn
- 3. Ellison J, Shafer P, Cole MB. Racial/Ethnic And Income-Based Disparities In Health Savings Account Participation Among Privately Insured Adults. Health Aff (Millwood). 2020;39(11):1917-1925.

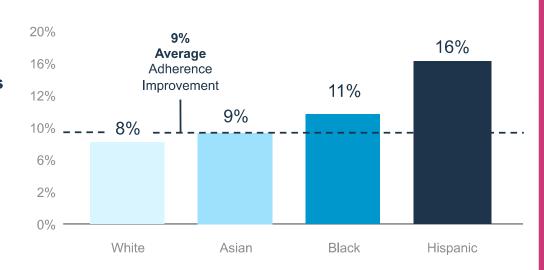
## Sharing Manufacturer Rebates Directly with Patients Is One Way to Improve Access, Especially for Black and Hispanic Communities

Sharing rebates directly with commercially-insured patients could **reduce**<sup>1</sup>:

- 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

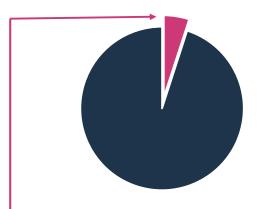
Sharing manufacturer rebates directly with commercially-insured patients can result in a 9% average improvement in adherence<sup>1</sup>

Adherence Improvement from Sharing Rebates on Oral Antidiabetic Drugs, by Race



<sup>1.</sup> The Impact of Sharing Manufacturer Rebates for Oral Anti-Diabetic Medications at the Point of Sale with Patients in the Commercial Market: Analysis by Race and Ethnicity, GlobalData, 2022. Available at: https://www.globaldata.com/reports/1-the-impact-of-sharing-manufacturer-rebates-for-oral-anti-diabetic-medications-at-the-point-of-sale-with-patients-in-the-commercial-market/

#### Value Assessment that Focuses on "Averages" Can Overlook Important Differences in Value of Medicines



Only 5% of cost effectiveness analyses (CEAs) recognize differences across race or ethnicity groups<sup>1</sup> Cost per quality-adjusted life year (QALY) for pneumococcal vaccine

Black population

\$44,000 per QALY

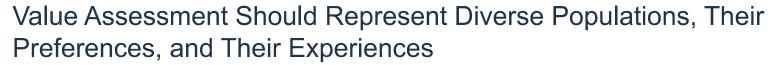
General population

\$81,000 per QALY

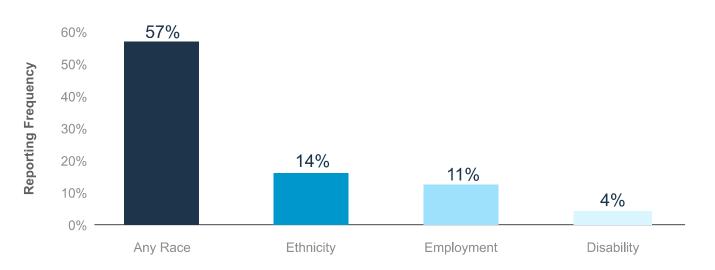
A pneumococcal vaccine given to older adults is estimated to be **more cost effective** for the Black population as compared to the general population due to disparities in childhood vaccination and underlying health conditions.<sup>2</sup> If coverage were determined based on value to an average patient, Black patients could be denied a treatment that is high value for them.

<sup>1.</sup> Lavelle, T. A., Kent, D. M., Lundquist, C. M., Thorat, T., Cohen, J. T., Wong, J. B., Olchanski, N., & Neumann, P. J. (2018). Patient Variability Seldom Assessed in Cost-effectiveness Studies. *Medical decision making: an international journal of the Society for Medical Decision Making*, 38(4), 487–494. https://doi.org/10.1177/0272989X17746989

<sup>2.</sup> Wateska AR, Nowalk MP, Lin CJ, et al. Cost-effectiveness of adult pneumococcal vaccination policies in underserved minorities aged 50-64 years compared to the US general population. *Vaccine*. 2019;37(14):2026-2033. doi:10.1016/j.vaccine.2019.01.002



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.<sup>1\*</sup>



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

<sup>1.</sup> Predmore Z, Huilgol S, Frank L, Concannon T. Representation and Equity in Utility Assessments Used for Cost-Effectiveness Analysis. ISPOR 2022 Conference. Poster Presentation. https://www.ispor.org/heor-resources/presentations-database/presentation/intl2022-3463/117163

<sup>2.</sup> Vyas D, Einstein LG, Jones DS. Hidden in Plain Sight – Reconsidering the Use of Race Correction in Clinical Algorithms. NEJM. 2020; 383:874-882. doi: 10.1056/NEJMms2004740.

## 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<sup>1</sup>

#### DID YOU KNOW?

Bias baked into medical algorithms can also result in less care being given to people of color.<sup>2</sup>

According to the QALY, the value of a life-saving treatment is assumed to benefit Black patients up to

10%

less than white patients.<sup>2</sup>



<sup>1.</sup> Bright J, Chapman RH. It's time to get health care value assessment right. STAT News, 2021. Available at: https://www.statnews.com/2021/04/15/health-care-value-assessment-get-it-right/#:~:text=Trying%20to%20gauge%20the,value%20assessment%20right%20is%20accelerating.

<sup>2.</sup> Broder M, Ortendahl J. Is Cost-Effectiveness Racist? Partnership for Health Analytic Research. 2021. Available at: https://blogsite.healtheconomics.com/2021/08/is-cost-effectiveness-analysis-racist/

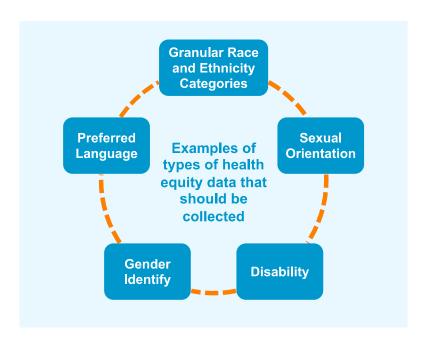
# Gaps in Health Data Collection Inhibit Our Ability to Identify and Address Health Disparities

#### Barriers to better health equity data<sup>1</sup>:

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

#### **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.<sup>2</sup>



- 1. Disparities in Data: Solutions and Barriers to Implementation, PhRMA, 2021, https://phrma.org/-/media/Project/PhRMA/PhRMA-Org/PhRMA-Org/PDF/D-F/Disparities-in-data Design 091621,pdf
- 2. Gordon NP, Lin TY, Rau J, Lo JC. Aggregation of Asian-American subgroups masks meaningful differences in health and health risks among Asian ethnicities: an electronic health record based cohort study. BMC Public Health. 2019;19(1):1551. Published 2019 Nov 25. doi:10.1186/s12889-019-7683-3

# 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



Section 3

PhRMA's Commitment to Building a More Equitable Health Care System for All





Illustration by Toya Beacham. Click here to learn more about the artist.

# 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

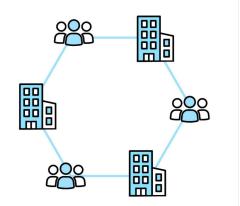






- ✓ A network
- Communications
- Community Relationships
- Ongoing site training
- Sustainable support
- Standardized platforms / metrics

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:





Yale school of medicine





Funded by a grant from PhRMA



#### Goals

- Show proof of concept for a comprehensive, collaborative **network of sustainable, connected, community-based sites** supporting clinical trial diversity in underserved communities.
- Partner with trusted messengers and community leaders to raise education, awareness, and support for clinical trial participation.
- Provide the resources and technical support for local sites to be successful, sustainable, and to thrive.
- 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 multistakeholder 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

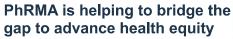
Florida, Tallahassee and Gainesville, FL



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







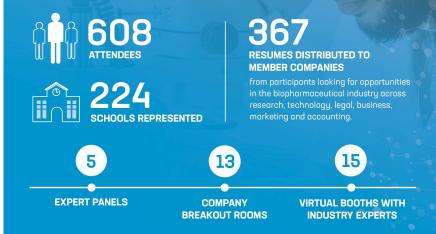
Breaking Down Barriers to the Uptake of COVID-19 Vaccines by Local African and African American Communities in Portland **Bridge-Pamoja**, Portland, OR



# 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 <a href="mailto:phrma.org/equity">phrma.org/equity</a>

