MILKEN INSTITUTE

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Health Equity in Science

A GIVING SMARTER GUIDE

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ABOUT US

About the Milken Institute

The Milken Institute is a nonprofit, nonpartisan think tank focused on accelerating measurable progress on the path to a meaningful life. With a focus on financial, physical, mental, and environmental health, we bring together the best ideas and innovative resourcing to develop blueprints for tackling some of our most critical global issues through the lens of what's pressing now and what's coming next.

About Milken Institute Strategic Philanthropy

Milken Institute Strategic Philanthropy advances the strategic deployment of philanthropic capital to create a better, more equitable world. We tackle persistent societal challenges by giving philanthropists insights, tools, and strategies to take big risks and test bold ideas.

About the Science Philanthropy Accelerator for Research and Collaboration

The Milken Institute's Science Philanthropy Accelerator for Research and Collaboration (SPARC) works to develop, launch, and lead initiatives that fund medical research and invest to accelerate the development of tools and treatments that will bring better health to millions of people. Our expertise lies within a number of medical research fields, including neuroscience, mental health, oncology, rare diseases, and immunology. We partner with philanthropists, leading them through complex medical research and clinical systems and guiding pathways for philanthropy to create a healthy, equitable world.

FOREWORD

The Burroughs Wellcome Fund believes that scientific discovery holds power to transform lives by advancing health. Yet, to truly realize this transformative potential, we must ensure that scientific advancements benefit *all* people. For this purpose, we must ensure that benefits to *all* are intentionally part of the design of these scientific advancements, thus recognizing and correcting their current limitations, which are rooted in imbalances of power, representation, and access. Addressing these limitations is only the beginning of a journey to achieve equitable health outcomes for all.

With this goal in mind, we introduce this guide—the culmination of a comprehensive landscape analysis grounded in research and facilitated discussions with health equity partners. This guide highlights the strategic areas where philanthropic investments can have the most significant impact on advancing health equity. However, true progress requires more than strategic investments; it demands authentic community partnerships. We must listen to all voices, understand diverse needs, and collaborate with those most affected by inequities to co-create solutions. Utilizing the principles of collective impact, we can help shape a future in which scientific discovery benefits everyone, creating the opportunity to thrive.

Through this guide, we hope to inspire other philanthropies to join us in this critical work. We invite you to explore the opportunities presented herein and consider how your investments, partnerships, and actions can contribute to a more equitable health landscape. Together, we can create a future where health equity is not only an aspiration, but also a reality for all.

With gratitude and hope,

Tammy Collins, PhD, Eliza Gary, Mandeep K. Sekhon, and Louis Muglia, MD, PhD

BURROUGHS WELLCOME FUND

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EXECUTIVE SUMMARY

Health equity is the state in which every person has a fair and just opportunity to achieve the best possible health. Achieving health equity is challenging because of many factors, including socioeconomic disparities, racial and ethnic discrimination, educational inequities, geographic limitations, cultural and language barriers, environmental exposures, political influences, and social factors such as the availability of housing, transportation, and social support systems. All of these factors affect who is involved in scientific research, what scientific questions are asked, and how scientific funding is directed, which has led to inequities in how science is conducted, who can access care, and the quality of health outcomes.

The COVID-19 pandemic and social justice movements of 2020–2021 sparked global action to change the status quo and advance equity. The pandemic highlighted and intensified disparities in infection rates, health-care access, and economic impacts, underscoring the critical need for more equitable health-care systems and outcomes. At the same time, social justice movements, such as those advocating for racial equity, brought attention to the deep-rooted inequities permeating all societal systems. The combined focus on health inequity and social injustices led to increased advocacy for inclusive approaches to biomedical research and health policy, along with demands for greater accountability to dismantle barriers to equitable treatment and care. However, many longstanding experts in health disparities recognized that these urgent calls for system reforms to ensure health justice for all individuals would be fleeting.

Since 2020, although there has been increased acknowledgment of health disparities, progress has been incremental. Some of the initial progress has stalled or reversed as a result of the 2023 Supreme Court decision to end affirmative action in higher education, which led to the removal of race-conscious admissions processes at US colleges and universities. This stirred US-wide activity to dismantle diversity, equity, and inclusion (DEI) initiatives not only in higher education but also in government, industry, and the corporate sector. Although health equity experts have observed similar reversals before, there is no doubt that a loss of momentum surrounding these issues could have devastating impacts on global health.

To tackle these emerging challenges and ongoing systemic barriers contributing to health inequities, key stakeholders—including government agencies, philanthropic organizations, academic institutions, industry, community-based organizations (CBOs), and health-care providers—must strive to enhance health outcomes and reduce disparities both independently and jointly.

In 2024, the Milken Institute's Science Philanthropy Accelerator for Research and Collaboration (SPARC) partnered with the Burroughs Wellcome Fund to conduct a comprehensive landscape review of the state of health equity in science to facilitate a greater understanding and identify areas where philanthropic support could inspire action. This *Giving Smarter Guide* describes emerging trends, key stakeholders, funding patterns, critical barriers to progress, and areas of opportunity that philanthropy is uniquely suited to address. The opportunities highlighted offer a path forward for interested funders looking to drive significant impact at the intersection of health equity and science.

PHILANTHROPIC OPPORTUNITIES TO ADDRESS SCIENTIFIC AND SYSTEMIC NEEDS

The philanthropic investment opportunities outlined in this *Giving Smarter Guide* were informed by a thorough review of the scientific literature, an examination of public and private funding patterns, and conversations with more than 40 experts and stakeholders spanning multiple sectors, including academia, industry, research institutes, government entities, nonprofit organizations, and CBOs. These individuals represented the research spectrum all the way from foundational science research to clinical care. Guided by their insights, Milken Institute SPARC identified five high-priority opportunities where philanthropic investment could have a transformative impact on health equity.

Opportunity 1: Build Community-Centered Research Systems. Community-centered research is at the core of advancing health equity in science. It guarantees that the voices and needs of those most impacted by health disparities are directly incorporated into the research process. Philanthropic funding can help strengthen research systems by establishing digital health technology hubs for equitable outcomes, networking community-led research, supporting community navigators, and investing in communities.

Opportunity 2: Expand Efforts and Collaboration. Scaling up and creating networks to facilitate collaboration is crucial for sustaining health equity efforts. Harnessing collective expertise and resources is essential to produce broader solutions that address health inequities on a systemic level. Philanthropic investment can help build a comprehensive health equity resource database, form a consortium of health equity in science funders, and support interdisciplinary and implementation research partnerships with Minority-Serving Institutions (MSIs).

Opportunity 3: Train a Diverse and Interdisciplinary Workforce. Developing the health equity workforce is fundamental for driving progress, as it integrates cultural competency and interdisciplinary thinking into research. Philanthropy can expand programs and training in interdisciplinary methods across the entire educational and workforce pipeline. In particular, it can bring diverse computational and AI expertise to biomedical research to create a more inclusive field that is primed for the challenges of tomorrow.

Opportunity 4: Catalyze Transformative Health Equity Research for Effective Implementation and Care. Encouraging equitable health implementation research is crucial for advancing more inclusive, community-centered care. Philanthropy can play a key role by prioritizing equity-driven molecular medicine and care-focused research and elevating health equity champions to break down barriers and foster a more inclusive research ecosystem.

Opportunity 5: Measure Impact and Emphasize Continuous Improvement. Standardized efforts and consistent tools are crucial for broad health initiatives to accurately assess progress, identify effective interventions, and ensure accountability. Philanthropy can support the development of a system of evidence-based practices, strategies, and tools to reliably measure health equity outcomes.

OVERVIEW OF THE INTERSECTION BETWEEN HEALTH EQUITY AND SCIENCE

> "Health equity is the state in which everyone has a fair and just opportunity to attain their highest level of health. Achieving this requires ongoing societal efforts to address historical and contemporary injustices; overcome economic, social, and other obstacles to health and health care; and eliminate preventable health disparities."
>
> —*Centers for Disease Control and Prevention, from 2024 Health Equity Outlook Report*

In 2021, the US allocated 17.8 percent of its gross domestic product (GDP) to health care, almost double the average expenditure of countries in the Organisation for Economic Co-operation and Development. Despite leading in spending, the US ranks poorly in health outcomes, with the lowest life expectancy at birth, highest rates of death from preventable conditions, highest maternal and infant mortality, and some of the highest suicide rates. Socioeconomic health disparities are a major factor contributing to these poor outcomes, imposing significant costs on the health-care system and the broader economy.

A 2023 National Institutes of Health (NIH)-funded study highlighted that racial and ethnic health disparities cost the US $451 billion in 2018, up 41 percent from $320 billion in 2014. Education-related health disparities for those without a college degree amounted to $978 billion in 2018, nearly double the annual growth rate of the US economy. Thus, addressing health equity is both an ethical and economic imperative for the US health-care system. There is a dearth of research focusing on the health of various underserved and marginalized communities (described in **Table 1**), which results in continued disparities for these populations.

TABLE 1: Populations Excluded from Research

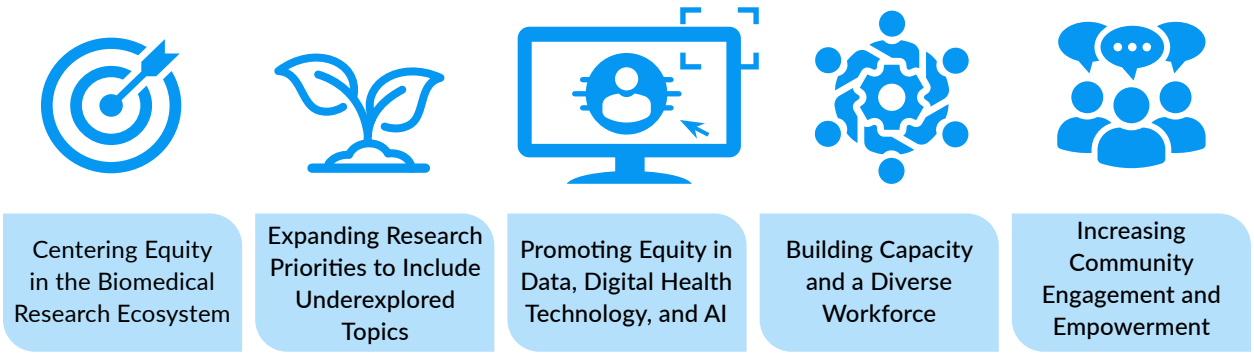
POPULATION	EXAMPLE
Women and Pregnant Individuals	Women remain underrepresented in research studies, although some progress has been made. For example, despite cardiovascular disease (CVD) being the leading cause of death in women, especially minoritized women, underrepresentation in CVD trials has been ongoing for decades. From 2010 to 2017, a review of 740 completed trials revealed that of a total of 862,652 adults, only 38.2 percent were women. There is an ongoing need to address the higher rates of maternal morbidity and mortality experienced by women of color: Black pregnant patients are three times more likely to die than their White counterparts. Contributing factors include access to prenatal care, socioeconomic status, underlying health conditions, and systemic biases.

Racial and Ethnic Groups	Groups such as Black, Hispanic/Latinx, American Indian/Alaska Native, Middle Eastern/North African, Asian, Native Hawaiian, and Pacific Islander lack adequate representation in research. Nearly 40 percent of the US population consists of minority racial and ethnic groups, yet 75 percent of the 32,000 participants in clinical trials for 53 new US Food and Drug Administration (FDA)-approved drugs in 2020 were White. This over-representation contrasts with the higher rates of chronic diseases in minority groups, who need better access to these trials. For instance, Black individuals represent 12.4 percent of pancreatic cancer cases but only 8.2 percent of participants in related clinical trials. Worldwide, Indigenous and tribal communities face profound health disparities, yet research focused on these groups is underfunded. Native American and Alaska Native life expectancy is five to ten years shorter than the US average.
LGBTQIA+ Community	The LGBTQIA+ community—especially transgender individuals—are often excluded from large-scale mental health studies. These individuals often have elevated rates of depression, anxiety, substance use, suicide, and tobacco-related cancer compared to the rest of the population.
Older Adults	As the global population continues to age, there is a growing need for more research on the health of older adults, particularly those from underrepresented groups. Research funding often does not reflect the potential impact of improving the quality of life and reducing health-care costs associated with better geriatric care.
Rural Communities	Rural communities include more than 60 million individuals in the US and encompass rural tribal communities. Individuals in these communities often experience unique health challenges, such as higher rates of chronic disease, limited access to health-care providers, and greater logistical barriers to health-care access.
Individuals with Disabilities	People living with disabilities—an estimated 12 to 30 percent of the US population—face significant health disparities, including higher rates of chronic conditions, mental health issues, and reduced access to preventive care. However, nearly 75 percent of clinical trials either directly or indirectly exclude people with intellectual and developmental disabilities.
Immigrants and Refugees	These groups are up to 2.5 times more likely than the general population to be uninsured and are at increased risk for mental health conditions such as post-traumatic stress disorder.
Currently or Recently Incarcerated Individuals	The rate of HIV among incarcerated individuals is more than three times that of the US general population. Rates of mental health issues and chronic diseases are also elevated. Furthermore, recently released individuals are at a significantly higher risk of death, especially from drug overdose. This elevated risk is linked to the lack of access to health services, substance use treatment, and continuity of care.

Source: Milken Institute (2024)

To address the inequities, challenges, and outcomes described above, biomedical research should be rooted in equitable practices to achieve health equity for all individuals. Stakeholders across sectors can drive progress in all aspects of research while improving health outcomes for all communities. **Figure 1** highlights the key topics that are essential to improving the intersection of health equity and research.

FIGURE 1: Overview of Needs to Advance Health Equity in Science



Source: Milken Institute (2024)

Centering Equity in the Biomedical Research Ecosystem

The intentional integration of health equity concepts into the full life cycle of biomedical, clinical, and regulatory research is crucial—and gradually increasing. From hypothesis formation, data collection, and analysis, to the dissemination of findings, researchers are beginning to adapt their approach. This includes considering which questions to ask and by whom, how analytical methods might introduce bias, and whether research findings are translated back to community members. There is also a growing recognition of the value of **community-based and patient-centered research** that poses research questions and conducts culturally sensitive research based on community needs, ensuring outcomes are directly relevant. Scientific funders are also beginning to shift toward more equitable grantmaking practices, including implementing equity scorecards to evaluate proposals and standardizing grant applications. To truly advance health equity, such practices will need to become the norm. **Figure 2** provides an overview of additional ways in which the research landscape is evolving.

FIGURE 2: An Evolving Research Landscape with an Increased Focus on Health Equity

Increased Consideration for Social Determinants of Health

Life expectancy in the US can vary by **15 years** depending on income level, education, and where an individual lives.

40% of modifiable contributors to health outcomes are attributed to socioeconomic factors (education, employment, income, social support, community safety, etc.).

10% are determined by one's physical environment (air and water quality, housing, transit, etc.).

Research is increasingly focusing on addressing these root causes of health inequity and understanding how multiple overlapping and intersectional social identities (such as race, gender, socioeconomic status) contribute to health disparities.

Expanding Technology for Equity

2024: The Office of the National Coordinator for Health Information Technology updated its Health IT Certification to consider health equity throughout the technology design, build, and implementation processes.

Technology such as mobile health applications, telemedicine, and AI is expanding and can overcome barriers to access in underserved areas.

Technology can also enhance diagnostics, predict health risks, personalize treatment plans, and identify larger trends to address public health issues.

There is a growing recognition that health technology needs to be researched, developed, and deployed with equity in mind.

Enhancing Diversity, Equity, and Inclusion in Clinical Trials

The comprehensive 2022 report from the National Academies of Sciences, Engineering, and Medicine showcases the significant push to make clinical trials more inclusive and diverse, by targeting underrepresented populations and those with the highest disease burdens.

2024: The Food and Drug Administration is requiring Diversity Action Plans for all Phase 3 clinical trials and pivotal studies to ensure the representation of historically underrepresented populations.

May 2024: *The Milken Institute report Toward a National Action Plan for Achieving Diversity in Clinical Trials outlines steps that organizations and sectors can take to establish a clinical trials system that is diverse, equitable, inclusive, and accessible to everyone.*

Increased Focus on Implementation Science

Implementation science studies how interventions perform in diverse settings to develop tailored strategies for individuals from across racial/ethnic groups and socioeconomic backgrounds.

It facilitates the integration of evidence-based interventions/practices into regular use by providers.

Learning health systems aim to rapidly translate research findings into practice and rely heavily on implementation science to ensure the timely delivery of evidence-based care.

Since 2021, *health-care organizations have been encouraged to become learning health systems to accelerate the translation of research into clinical practice and the development of interventions to improve quality, value, safety, and equity in patient care.*

Source: Milken Institute (2024)

Expanding Research Priorities to Include Underexplored Topics

Addressing health equity requires attention to a broad spectrum of research areas, many of which have historically been underfunded and, therefore, underexplored. In particular, the historical neglect of marginalized groups in research has led to extensive gaps in scientific knowledge and poorer health outcomes for these populations. Several key areas that are especially underfunded, both historically and in current settings, are described below.

Systemic Factors

Despite the known impact of social determinants of health (SDOH) as described in **Figure 2**, these areas have often been overlooked in favor of more direct clinical interventions. One major SDOH is born from the construct of race. Although race is often perceived as a biological distinction, it is, in fact, a social construct with no basis in human genetics. This misunderstanding perpetuates stereotypes, discrimination, and systemic inequalities. Research addressing the impacts of systemic and structural racism on disease treatments, health outcomes, and access to care is profoundly underfunded. There is an urgent need for increased funding to understand what interventions addressing SDOH would also effectively reduce health inequities. Furthermore, understanding SDOH offers insights into how to dismantle the barriers they create and foster research environments that promote true equity for health outcomes.

DEFINITION: SYSTEMIC AND STRUCTURAL RACISM

Systemic racism refers to the widespread exclusion of certain racial and ethnic groups from resources and opportunities.

Structural racism occurs when such discrimination is embedded in the laws, policies, and practices of social institutions.

In the biomedical ecosystem, these manifest as biases in medical and scientific training, disparities in the focus of clinical research, and inequitable health-care policies that disproportionately affect marginalized populations.

Source: Milken Institute (2024)

The influence of corporate practices and political decisions on health is another significant yet often underfunded area of research. Corporate behaviors—such as marketing unhealthy foods, environmental pollution, and labor practices—can have profound impacts on health. Similarly, federal, state, and local policies can determine the allocation of resources and the accessibility and regulation of harmful substances, all of which directly affect health outcomes. Research into how these systemic political and corporate factors shape health outcomes is crucial for developing strategies that mitigate negative influences and promote positive health behaviors and environments.

Foundational Science and Systematic Reviews

Foundational science and systematic reviews play crucial roles in advancing health equity by providing the rigorous and comprehensive evidence base necessary for effective interventions and policies. Foundational science, which includes basic biomedical and social science research, lays the groundwork for understanding the fundamental mechanisms of disease progression. This biological understanding is essential for developing targeted therapies, preventive strategies, and

interventions that can address health disparities at their roots. However, basic biomedical research often relies on samples from a homogenous population without considerations for sex differences or genetic diversity.

Systematic reviews consolidate and evaluate the results of multiple studies, offering a high level of evidence by summarizing what is known about a particular topic. Systematic reviews are particularly important because they can reveal gaps in research, highlight areas where certain populations are underrepresented, and identify interventions that are effective in diverse settings. This knowledge can guide future research priorities, which is critical for directing resources and efforts toward the areas most likely to yield improvements in health equity.

Action-Oriented Research

Action-oriented research typically involves developing, testing, and scaling interventions that are specifically designed to improve health outcomes in underserved and marginalized populations. In recent years, there has been a noticeable shift in the focus of both federal and private organizations toward research that not only maps out the intricacies of health inequities but also actively works toward mitigating them. This trend reflects a growing recognition that although it is important to understand where health disparities exist, it is equally crucial to implement solutions that directly address these issues. Action-oriented research is proactive and pragmatic, aiming to quickly translate findings into tangible health improvements. This shift in research emphasis is accompanied by greater collaboration between different stakeholders, including academic institutions, clinical care providers, community groups, and policymakers. This type of research—exemplified by the case study describing the Humana Foundation—often employs a greater use of technology and data analytics to measure impact and refine strategies in real time, ensuring that the interventions remain aligned with the community's evolving needs.

CASE STUDY

The Humana Foundation

The Humana Foundation presented $250,000 awards to each of four universities conducting solutions-focused research:

University of North Carolina (UNC) Gillings School of Global Public Health: an intervention study of the impacts of healthy, home-delivered meals and social connectedness programs for seniors with lower incomes

UNC School of Social Work: a study on the potential for racially and ethnically diverse high school peer leaders to improve suicide prevention programs

University of Texas Health Science Center at Houston School of Public Health: a produce prescription program examining the mental and physical health of overweight, at-risk children and their families

Yale School of Medicine: a study developing advanced care planning tools to improve mental health outcomes for caregivers of seniors living with dementia

Interdisciplinary Research and Collaboration

Interdisciplinary research integrates fields such as biomedical sciences, engineering, public health, sociology, economics, and environmental science while involving sectors such as education, housing, and employment. Combining diverse research perspectives and skills enhances our

understanding of how social determinants impact health across populations. This collaboration encourages innovative solutions that might not emerge within a single field and helps train new generations of researchers, clinicians, and providers to think broadly and act comprehensively. Interdisciplinary research can address the complexity of factors contributing to health inequities, propose integrated solutions, and foster a cooperative biomedical ecosystem. By presenting unified evidence from multiple fields, researchers can make a more compelling case for the changes needed to promote health equity. For example, research that combines urban planning, public health, and sociology has demonstrated how the built environment affects health outcomes, showing that access to green spaces, walkable neighborhoods, and affordable housing can reduce obesity rates, improve mental health, and enhance overall quality of life, especially in low-income communities. Initiatives such as Complete Streets involve urban planners, public health experts, and community advocates to create safer, more accessible streets for all users. This and other examples illustrate the opportunity to build on interdisciplinary approaches as a best practice for advancing health equity.

EXAMPLE INITIATIVES
Interdisciplinary Research and Training

NIH Common Fund Program: Transformative Research to Address Health Disparities and Advance Health Equity	UNC Interprofessional Graduate Certificate in Improvement Science and Implementation
Funds innovative research projects that have the potential to create or reshape fundamental paradigms to address health disparities and advance health equity. Encourages interdisciplinary teams to develop transformative solutions that could have a profound impact on the health of underserved and marginalized populations.	Incorporates interdisciplinary training to prepare professionals to think outside their immediate fields of expertise and communicate and collaborate across disciplines. Prepares students from across education, health care, and social services.

Critical Public Health Topics

Addressing public health topics such as climate change, infectious disease, mental health, and health literacy is critical to achieving health equity. However, studies focusing on the intersection of these topics with health disparities remain underfunded. For example, climate change disproportionately affects vulnerable populations, including low-income communities, Indigenous groups, and those living in areas prone to severe weather events and pollution. These populations are more likely to face risks such as heat-related illnesses, respiratory conditions from poor air quality, and diseases spread by vectors that thrive in changing climates. Research into how climate change exacerbates health disparities and strategies to mitigate these effects is vital. Increased investment in this area would enable the development of adaptive public health strategies that protect the most affected populations and promote health equity in the face of global climate challenges.

Research focused on mental health, specifically for marginalized and underserved communities, is another area that remains underfunded. Mental health inequities persist particularly among racial and ethnic minorities, largely because of unequal access to care, cultural stigma, and a shortage of culturally competent providers.

In May 2024, Meharry Medical College School of Global Health and the Deloitte Health Equity Institute released the report, *The Projected Costs and Economic Impact of Mental Health Inequities in the United States*. The estimated total cost attributable to mental health inequities will be $14 trillion between 2024 and 2040, specifically because these inequities exacerbate other chronic conditions such as diabetes, obesity, hypertension, and stroke.

Promoting Equity in Data, Digital Health Technology, and AI

Having access to complete, diverse, and quality data is at the core of advancing health equity. Across sectors and disciplines, the capacity to address health inequities is limited by data quality. Certain types of data are essential to meaningfully achieve health equity, yet they are often missing or inadequately captured in current research and clinical databases. The gaps in data collection and analysis significantly hinder efforts to fully understand and resolve health disparities. With the evolution of research practices toward equity, there is increasing consideration for how data are collected, standardized, analyzed, and shared. Discussions around ethics, provenance, sovereignty, use, availability, and accessibility are also gaining traction, promoting the responsible use of inclusive datasets. Finally, the development of equitable digital health technology and AI tools rests heavily on having the right data from diverse groups to ensure there is no bias that can lead to harmful outcomes. These topics are expanded on in the sections below.

Data Collection

Efforts are increasing to expand data collection to include underrepresented populations that have historically been excluded from research. Additionally, the use of real-world data (RWD) from electronic health records (EHRs), insurance claims, wearables, satellites, and mobile apps is increasing. Together, these data provide a more accurate and comprehensive picture of patient health outcomes and behaviors in real-life settings, which is crucial for understanding and addressing health disparities across different communities. (Specific types of data that will need to be collected are included in **Table 6** of the Appendix.)

Additionally, longitudinal studies, which track the same individuals over extended periods, provide insights into disease progression, the long-term impacts of SDOH, and the effectiveness of interventions across different stages of life. Investments in longitudinal data can help identify critical periods for intervention, monitor the long-term safety and effectiveness of treatments, and provide a deeper understanding of the life-course influences on health disparities.

EXAMPLES
Equitable Data Collection Efforts

Real-world Accelerator to Improve the Standard of collection and curation of race and Ethnicity data in healthcare (RAISE) Action Framework

Led by the Reagan-Udall Foundation for FDA.

Focuses on improving the collection and utilization of race and ethnicity information in RWD to ensure that health data are comprehensive and uniformly collected across various platforms.

NIH *All of Us* Research Program

Gathering health data from 1 million diverse individuals in the US.

87% of enrolled participants are from underrepresented groups.

Collecting a wide range of health data, including genomics, EHRs, SDOH, surveys, and wearables.

CONTINUING CHALLENGES: Data Collection

Accurately collecting race and ethnicity data has been an ongoing challenge for decades. In March 2024, the Office of Management and Budget revised the standards for how federal data are collected for the first time since 1997. Updates include a combined race/ethnicity question, the addition of a Middle Eastern or North African category, and the collection of detailed race/ethnicity data on top of the minimum categories. While this is some progress for federal data, other sectors have developed their own detailed race/ethnicity categories with no standardization, making it difficult for analysis.

Data Sharing, Standardization, and Analysis

All across the biomedical research ecosystem, emphasis on data sharing and collaboration between institutions and disciplines is growing. The NIH Data Management and Sharing Policy mandates that funded researchers share their data through publicly accessible repositories for broader access to valuable datasets, enhancing the reproducibility and transparency of research findings. Efforts to standardize data formats so that data shared from different sources are compatible and can be combined for more robust analyses are also increasing. Data disaggregation—by multiple variables, such as race, ethnicity, gender, age, socioeconomic status, and geographic location—continues to be emphasized, especially in the context of health equity. Disaggregated data would enable researchers to uncover subpopulation nuances that might be obscured in aggregated data. Additionally, there is a significant move toward integrating different data types from multiple sources into multimodal datasets to gain a holistic understanding of health determinants and tailor treatments more precisely. The UK Biobank is one of the world's largest multimodal databases, containing genomic information, clinical research data, EHRs, environmental data, and lifestyle data from half a million participants.

CONTINUING CHALLENGES: Data Disaggregation

Disaggregating data is a continuing challenge. For example, the categories of Asian American, Native Hawaiian, and Pacific Islander (AANHPI) encompass more than 50 ethnic groups, so research studies miss potential health-related differences between these groups. Collecting and analyzing data at such detailed levels can be challenging due to resource limitations, privacy concerns, and the complexity of managing large datasets with diverse variables. In July 2024, RWJF released a call for research proposals that yield recommendations for actionable Asian American subgroup categories to be applied in the collection and analysis of race and ethnicity data.

Data Ethics, Provenance, and Sovereignty

Policies and regulations have been enacted and continue to be updated to ensure the protection of research participants (especially vulnerable populations), ethical data practices, and stringent health data privacy and security measures. These include the Revised Common Rule, General Data Protection Regulation in the EU and the Health Insurance Portability and Accountability Act in the US. These regulations not only protect individual privacy but also ensure that health data are handled in a manner that promotes equity and trust.

With the increasing complexity of data pipelines in the biomedical ecosystem, advanced tools for tracking data provenance, such as blockchain, are becoming essential. These tools help trace the origin and lifecycle of data, documenting every instance of data handling from creation to use and beyond. This is important for health equity as it ensures that data used in research and decision-making are accurate and reliable and that data origins are transparent. Data sovereignty is also gaining importance, particularly in the context of global data exchanges and the local legal implications of handling sensitive health information. There is a growing trend toward individuals and communities asserting their rights over their data, especially for Indigenous and marginalized populations who may be vulnerable to data misuse. Decentralized data management systems—that reduce the risk of data breaches and unauthorized access—are emerging as a means to enhance data sovereignty and security.

The Native BioData Consortium was established in 2018 to create a biobank that ensures data protection and community control over biological samples for tribal communities. It addresses the challenges around tribal nation ownership, participant liability, and the desire for culturally sensitive data governance.

Digital Health Technology and AI

Digital health technology and AI offer novel opportunities to address long-standing inequities and enhance the inclusiveness and effectiveness of treatments and interventions. AI tools are increasingly employed to synthesize large datasets and develop predictive models that assess

the risk of disease or adverse health outcomes in different demographic groups. AI tools are also being used to enhance diagnostic accuracy, treatment personalization, and patient management, particularly in underserved regions where health-care provider shortages are common. Importantly, there is an increasing focus on the ethical development and use of AI in biomedical research to ensure that algorithms do not perpetuate existing biases. These efforts include considerations of how AI systems are designed, the data they are trained on, continuous monitoring and updating of algorithms, and the implications of their use. See the Milken Institute's *Transformative Computational Biology Giving Smarter Guide* for more information.

EXAMPLE INITIATIVE
Equitable AI

NIH's Artificial Intelligence/Machine Learning Consortium to Advance Health Equity and Researcher Diversity (AIM-AHEAD) Program

Ensures that AI and data-driven research include diverse populations to combat the widening of existing health disparities.

Incorporates MSIs such as Meharry Medical College, Morehouse School of Medicine, and Howard University.

While digital health technologies such as wearables, mobile health apps, and telemedicine can enhance access to health-care services, particularly in underserved areas, they also risk widening health disparities if not equitably implemented. Increasing technological literacy, affordability, and the availability of necessary infrastructure, such as reliable internet access, will support the equitable adoption of digital health technologies. Innovations in diagnostic technologies are also increasingly focusing on reducing biases that affect accuracy across different demographics. For example, for decades, studies have shown that pulse oximeters overestimate oxygen levels in individuals with darker skin tones, which finally came to light during the COVID-19 pandemic. In response, developments in technologies and diagnostic algorithms are being fine-tuned to account for variations in physiology and pathology across races, genders, and age groups. This includes redesigning tools such as pulse oximeters to provide accurate readings regardless of skin pigmentation and refining AI algorithms to remove racial/ethnic, gender, age, disability, and language biases.

Building Capacity and a Diverse Workforce

Capacity building and workforce development are essential to ensuring health equity is prioritized in the biomedical research ecosystem. Organizations must have the necessary infrastructure, resources, and proficiency to sustain and grow health equity research initiatives. This requires a commitment to DEI efforts and enhanced education and training around equity concepts and measures. These topics are expanded on in the sections below.

Diversity, Equity, and Inclusion Efforts

Stakeholders across the biomedical ecosystem have committed to enhancing DEI practices, even amid the recent backlash. Some organizations have started by looking inward to evaluate their grantmaking and investing processes and review their internal practices to track alignment with DEI initiatives. This includes examining staff representation, advisory committee make-up, board demographics, and DEI spending. Organizations are also increasingly instituting community advisory boards, which play a critical role in evaluating research protocols to ensure they address relevant and significant community health issues.

Efforts to broaden access to education in the fields of science, technology, engineering, mathematics, and medicine (STEMM) and increase recruitment and retention of underrepresented and marginalized groups have been ongoing for decades. However, continuous, sustained, intentional, and thoughtful investment is needed to develop a diverse STEMM workforce. These efforts must work all along the educational and workforce pipeline and can include targeted youth outreach, recruitment of underrepresented communities, online programs, alternative learning paths, scholarships, financial aid, and mentorship programs at the undergraduate, graduate, and postdoctoral stages.

CASE STUDY

The American Society of Human Genetics

In 2023, the American Society of Human Genetics (ASHG) released the report Facing Our History–Building an Equitable Future.

This report details the findings of a year-long effort to document and reckon with experiences of past injustices, as well as progress toward equity, in the human genetics research field and within ASHG.

This extensive internal review garnered a generally positive response, driving momentum and strategy for DEI efforts across ASHG.

Higher education institutions face considerable challenges in creating truly diverse, equitable, accessible, and inclusive campus environments, especially within STEMM disciplines. A 2021 National Science Foundation report found that Hispanic, Black, and American Indian or Alaska Native individuals—accounting for 37 percent of the US population—comprised a higher share of the skilled technical workforce (32 percent) than workers in STEM occupations with at least a bachelor's degree (16 percent). Persistent bias, marginalization, and exclusion based on factors such as gender, race, ethnicity, disability, socioeconomic status, sexual orientation, age, and first-generation college status hinder full participation. To address and dismantle these inequities, the American Association for the Advancement of Science (AAAS) SEA Change initiative uses a comprehensive self-assessment process to foster lasting improvements in STEMM DEI at US colleges and universities.

Investing in MSIs, such as Historically Black Colleges and Universities (HBCUs), Hispanic-Serving Institutions (HSIs), and Tribal Colleges and Universities (TCUs), is also crucial. The White House revealed in May 2024 that the Biden-Harris administration had invested more than $16 billion in federal funding to HBCUs from FY2021 to FY2024. This investment spans various topics and includes some health equity programs, such as the National Institute of Environmental Health Sciences (NIEHS) HBCU-Connect Initiative. Funders across sectors should leverage and expand this federal investment.

CONTINUING CHALLENGES: DEI Efforts

In light of the recent SCOTUS decision around Affirmative Action and the reversal of many DEI efforts at educational institutions across the US, initiatives to build a diverse and inclusive biomedical workforce need sustained support and strong leadership. Resistance to DEI efforts is leading to significant shifts in funding. Some stakeholders are navigating this landscape by adopting broader "all-access" language to protect DEI programs, but there are substantial concerns about legal repercussions and political backlash. Despite these challenges, some groups are doubling down and maintaining bold principles. For example, the NIH UNITE initiative, launched in 2021, continues to address structural racism within the biomedical research enterprise to reduce health inequities.

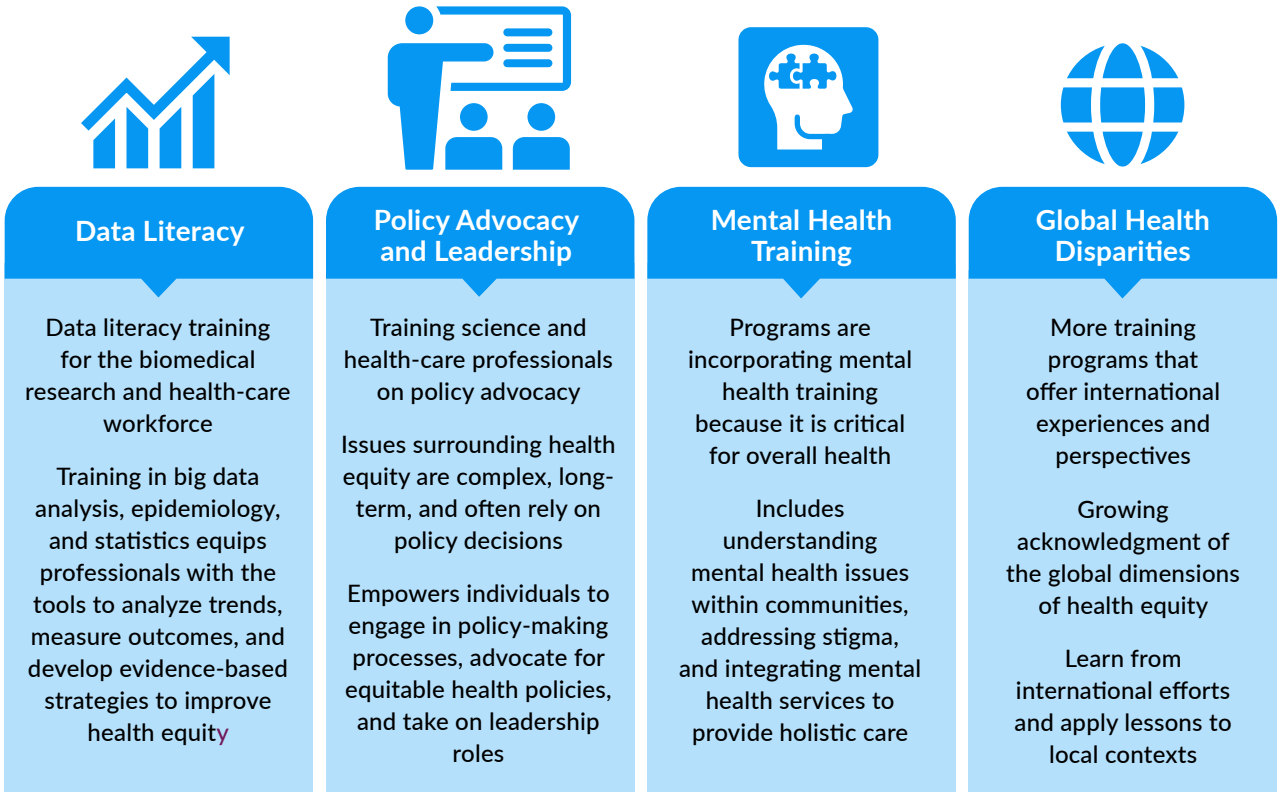
Education, Training, and Skill Building

Educational institutions are increasingly embedding health equity concepts into the core curricula of science and medical programs. This approach ensures that all biomedical professionals have a foundational understanding of the inequities that affect health outcomes and are equipped to address these issues in their future careers. Institutions and training programs should incorporate modules on DEI, bioethics, cultural competency, humility, and community engagement. These programs help educate scientists and health-care providers on how to integrate these issues into their work to improve data collection, research practices, and patient care.

The Broad Institute's Office of Inclusion, Diversity, Equity, and Allyship (IDEA) aims to build an inclusive culture and community to promote more equitable science. The IDEA Office provides educational resources and toolkits to bridge gaps in scientific training and supports researchers in engaging more thoughtfully with community-based participatory research (CBPR). The Broad Institute also holds an Equity in Biomedicine Seminar Series, which invites scientists and trainees to reflect on the social impact of their research.

In a move toward interprofessional education, there are also existing efforts that bring together individuals from various fields such as computer science, data science, biology, engineering, medicine, nursing, public health, and social work. These multidisciplinary programs and training opportunities are designed to break down silos and foster a collaborative approach, which is essential for developing holistic solutions to complex health equity problems. There is also a push for intersectoral collaboration involving policymakers, community organizations, and private-sector stakeholders to create comprehensive strategies for health improvement. **Figure 3** outlines some trends around training and skill-building for health equity.

FIGURE 3: Emerging Trends Around Education, Training, and Skill-Building to Advance Health Equity



Source: Milken Institute (2024)

CONTINUING CHALLENGES: STEMM Workforce Development

Early engagement of students from diverse backgrounds in STEMM fields is crucial for long-term workforce development. Disparities in access to quality K through 12 STEMM education—whether due to economic or geographic factors—pose a significant barrier, particularly in underserved communities. More initiatives to enhance STEMM education and outreach need to be implemented in K through 12 schools, focusing on inclusivity and engagement. In addition, supporting individuals during key career transitions in health and science fields is essential for retaining talent. Transition points, such as moving from student to professional or from clinical roles to research or leadership positions, can be particularly challenging for individuals from underrepresented backgrounds. These transitions often require navigating new environments, acquiring additional qualifications, and building new professional networks. Providing mentorship programs, career counseling, and networking opportunities tailored to these needs can help ease these transitions.

Working with Communities

A key part of organizational capacity building is recognizing the importance of community engagement in health equity research. There has been an increase in training for research and clinical care professionals to work effectively with CBOs and leaders. This approach not only ensures that treatments and interventions are more tailored and responsive to the needs of different communities but also empowers communities to take an active role in improving their health outcomes. An increased emphasis on CBPR further reflects a shift toward involving community members in the research process. This approach is integral in designing and

implementing health interventions that are not only effective but also culturally relevant and supported by those they aim to benefit. Capacity building is also evolving to include training community health workers and leaders in basic biomedical sciences and equipping them with the tools needed to advocate for and implement health improvements within their communities.

EXAMPLE INITIATIVES
Working with Communities

Wake Forest University's Maya Angelou Center for Health Equity	NIH *All of Us* Research Program
Builds relationships with caregiver, faith-based, and Indigenous community groups.	The Division of Engagement and Outreach works with researchers to foster meaningful relationships with community partners and ensure that community needs are central to the program's initiatives.

CONTINUING CHALLENGES: Capacity Building in Communities

Research and programs aimed at improving health equity often struggle to secure funding. Many organizations, especially in rural and underserved areas, lack the facilities and technology to support biomedical education and health-care delivery. Investments in infrastructure are crucial to eliminating these disparities. Bureaucratic delays and resistance to change within established systems can postpone the benefits of research findings, prevent timely responses to health crises, and hinder the adaptation of health services to meet changing community needs. A significant challenge in addressing health equity across various regions is the absence of a cohesive national strategy aligning local, state, and federal efforts with private and nonprofit initiatives. Without a unified approach, efforts to combat health disparities can be fragmented, inconsistent, and inefficient, leading to duplicated resources in some areas while others are completely neglected. It is crucial to establish more robust networks for collaboration and information sharing among stakeholders.

Increasing Community Engagement and Empowerment

The final trend critical for advancing health equity in science is increased community engagement and empowerment. To ensure that treatments, interventions, and policies are effective and equitable, organizations must involve diverse populations in research and decision-making processes. This requires a commitment to communication and outreach strategies as well as long-term trust-building and community partnerships, as described below.

Communication and Outreach Strategies

Listening and communicating are vital components of improving health literacy, combating misinformation, and establishing organizational standards to drive health equity. Organizations need to enhance communication strategies, develop tailored educational materials that are culturally and linguistically appropriate, and use community health workers to disseminate health information

effectively. There continues to be an emphasis on simplifying complex information, such as vaccine and regulatory processes, to improve accessibility, understanding, and engagement. This empowers individuals to identify misinformation and promotes awareness of health inequities. By inviting more community members to the table, organizations are learning to take input and co-create solutions that better serve these populations.

The use of digital platforms to engage communities has expanded dramatically. Mobile health apps, social media, and online forums are being used to gather input, disseminate information, and facilitate discussions about health issues. These tools are particularly valuable in reaching younger populations and those in remote or underserved areas. Initiatives are increasingly engaging youth as advocates, educators, and leaders in health, providing them with the tools to influence their communities and policies at various levels. Lastly, organizations are working to carefully define health equity terms, goals, and metrics to unify their efforts, with clear roles and best practices to support cross-disciplinary, cross-sector dialogues.

Building Trust and Partnerships with Communities

Building trusting relationships between researchers, health professionals, and communities is crucial for effective engagement, especially in historically marginalized groups that have experienced medical mistrust. This requires open communication, involving community leaders in decision-making, and incorporating community feedback into program development. Community navigators play a key role in connecting people to resources and guiding them through complex systems to overcome barriers. Strong partnerships with local organizations, businesses, and stakeholders help pool resources, share knowledge, and ensure that health equity initiatives are more adaptive, culturally responsive, and supported by the community, leading to better health outcomes and resilience. Successful examples include projects addressing health disparities in Black, Hispanic, and Indigenous communities, where community input has directly influenced research priorities and interventions. In addition, patient navigator programs have been found to increase cancer screening rates and follow-up care in marginalized communities. While these efforts are promising, ongoing challenges remain. Long-term, continuous funding for efforts and programs focused on building trust with communities is lacking and is an area where philanthropic funding can play a catalytic role.

Empowerment through Data, Research, and Advocacy

More and more, communities are being empowered to use data to advocate for better health services and policies. Initiatives that train community members to collect, analyze, and use data relevant to their health concerns are helping to transform scientific research and drive evidence-based advocacy and decision-making.

Community empowerment initiatives promote a sense of ownership among community members, leading to higher engagement and better outcomes. They also recognize existing community strengths and assets instead of focusing solely on needs or deficits. For example, integrating Indigenous knowledge into scientific research and health-care delivery validates the experiences and practices of these groups while leading to more widely accepted health solutions. Finally,

MODELS OF COMMUNITY EMPOWERMENT

Community-Based Participatory Research	Community-Led, Place-Based Initiatives
CBPR has gained significant traction as a research approach in public health, medicine, and nursing. It directly involves community members with lived experience throughout the research process, from defining the problem to developing solutions and disseminating findings. This emphasizes mutual respect and shared decision-making between researchers and community participants. It also encourages equity in research participation, promotes sustainable public health programs, advances health disparities research, and explores culturally tailored interventions.	These harness the unique strengths of local communities to design and implement solutions that are culturally relevant. By empowering communities to lead and manage their own health projects, these initiatives ensure that the interventions are deeply rooted in the actual needs and preferences of the community members. Examples include research projects, local health education programs, community-managed health-care facilities such as birthing centers, and public health campaigns that gather real data on environmental conditions in susceptible communities.

community groups are increasingly involved in advocacy to influence health policy. By empowering communities to participate in policy development, their specific needs and perspectives are more likely to be considered, leading to more equitable and actionable health policies. However, the Supreme Court's 2023 decision to eliminate affirmative action in college admissions is having a ripple effect on these efforts, with organizations and institutions that use data to advocate for

EXAMPLE INITIATIVES
Community Empowerment

In Our DNA SC

A community health research initiative started by the Medical University of South Carolina, focused on examining how DNA affects health.

Seeking to enroll 100,000 participants for free genetic testing.

The project aims to enhance access to personalized health care and support new research breakthroughs.

Participants receive confidential results regarding their genetic risk for certain cancers and heart disease and information about proactive health-care planning.

NIH's Community Partnerships to Advance Science for Society (ComPASS) Program

Develop, share, and evaluate community-led health equity structural interventions that leverage partnerships across multiple sectors to reduce health disparities.

Develop a new health equity research model for community-led, multisectoral structural intervention research across NIH and other federal agencies.

Examples of funded studies: Community-Led Structural Intervention to Address Health Consequences of Community-Police Interactions in Tarrant County, Texas, and Neqkiuryaraq–The Art of Preparing Food, an intervention study to improve the life expectancy of Alaskan Native Tribes in the Yukon-Kuskokwim Delta.

community needs now navigating a more challenging environment. The decision could limit race-conscious data collection and reporting practices that have been crucial for identifying disparities and advocating for equitable resources. Such limitations may affect the ability of community organizations to use data effectively for advocacy purposes since legal uncertainties around race-based considerations could stifle open discussions and action plans for equity.

GLOBAL INVESTMENT IN ADVANCING HEALTH EQUITY RESEARCH

The Milken Institute SPARC created *Health Equity in Science: A Stakeholder and Funding Analysis* as a companion document to this Giving Smarter Guide. It contains detailed information on the stakeholder and funding landscape of health equity in science. The following sections summarize certain key components.

Health equity is a growing global priority, driven by the understanding that addressing health disparities is essential for improving overall health outcomes and achieving economic stability. The COVID-19 pandemic highlighted and exacerbated health inequities, leading to a stronger global call for equitable access to vaccines, treatments, and health-care resources. Furthermore, the global climate crisis has exposed the disproportionate effect of extreme weather events, changing disease patterns, food and water insecurity, and displacement on the health of marginalized communities, including Indigenous peoples and those in low- and middle-income countries. Therefore, health equity has been a significant focus of international cooperation and funding across governments, nongovernmental organizations, and philanthropy. Countries are increasingly incorporating health equity into their national health policies and programs, recognizing that reducing health disparities can lead to better health outcomes and sustainable development. International organizations such as the United Nations and its specialized agency, the World Health Organization, have stressed the importance of reducing health inequities, particularly focusing on social determinants such as poverty, education, food and water insecurity, and gender equality. These and other prominent stakeholders are outlined in **Table 2**.

TABLE 2: Prominent International Organizations with Health Equity Programs

ORGANIZATION	PROGRAMS AND INITIATIVES
European Commission	• Funding initiatives are primarily carried out through the EU4Health program, the largest health program ever funded by the EU, with a budget of €5.3 billion for 2021–2027. • Aims to improve health in the EU by enhancing crisis preparedness, funding health promotion and disease prevention strategies, strengthening health systems and the health-care workforce, investing in digital health solutions, and funding cancer prevention programs.

United Nations	• 2015: adopted the 17 Sustainable Development Goals (SDGs) to end poverty, improve health and education, reduce inequality, spur economic growth, and tackle climate change by 2030. • 2024 SDG Progress Report: Only 17 percent of the SDG targets are on track to be achieved, nearly half are showing minimal/moderate progress, and over a third have stalled or regressed.
World Health Organization	• Released a report on January 18, 2024, containing an operational framework for monitoring SDOH. The framework provides countries with guidance on tracking these determinants, implementing actions, and leveraging data for policy initiatives across various sectors.
EuroHealthNet	• A nonprofit partnership among European organizations, agencies, and statutory bodies working on public health, disease prevention, health promotion, and reducing inequalities.

Source: Milken Institute (2024)

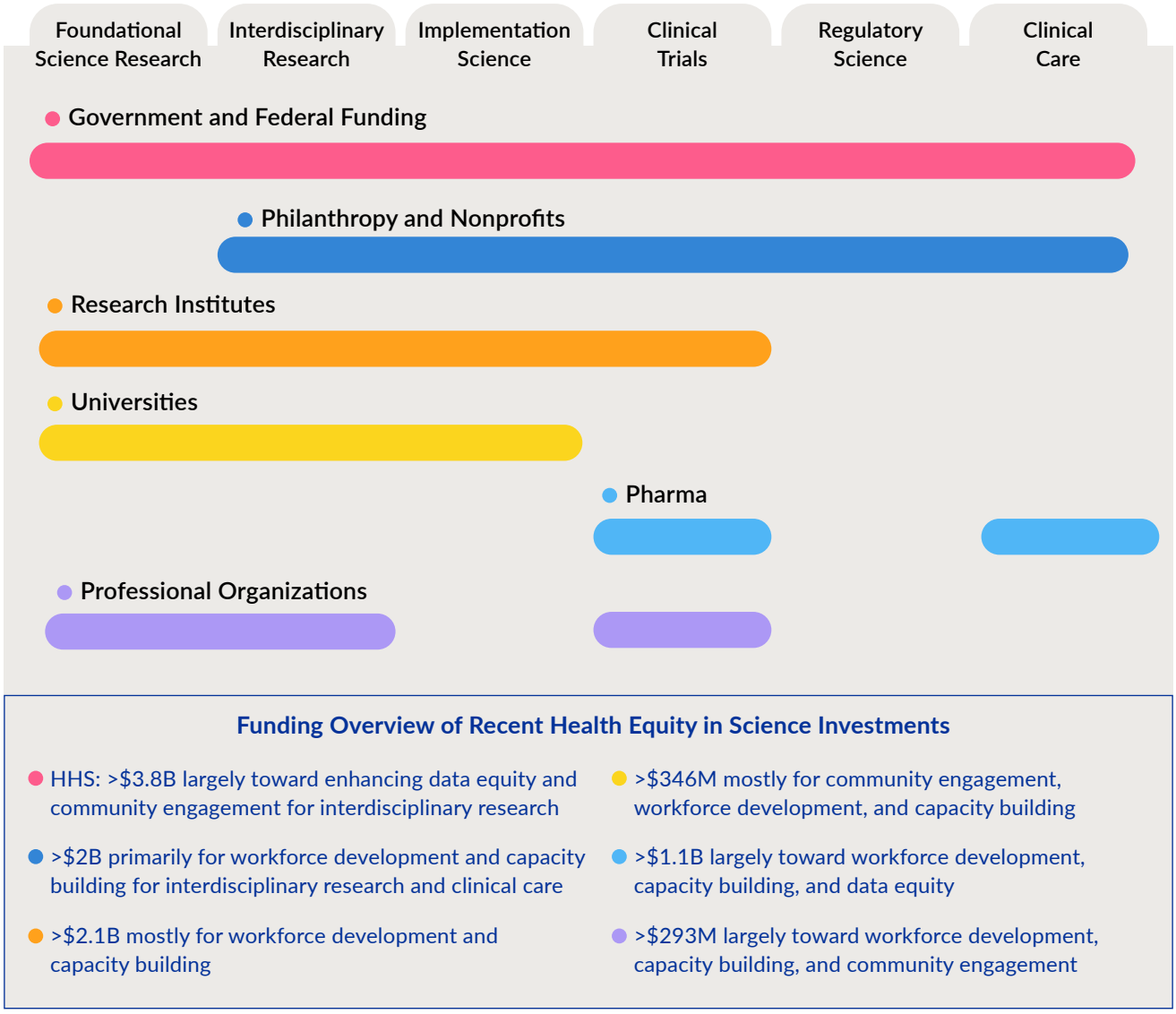
SPARC's analysis indicated that the primary focus areas for many global health equity initiatives include health system strengthening, digital health solutions, crisis preparedness, disease prevention, SDOH, vaccine access, immunization programs, health equity research and policy development, universal health coverage, climate and health, community health initiatives, sexual and reproductive health rights, and international cooperation and partnerships. While these approaches have led to improved health outcomes, there is still much to do and there has thus far been less focus on equity in biomedical and clinical research practices.

KEY STAKEHOLDERS AND FUNDING OVERVIEW IN THE US

SPARC's *Health Equity in Science: A Stakeholder and Funding Analysis* companion document contains detailed information on the stakeholder and funding landscape of health equity in science. The following sections summarize certain key components.

The key stakeholders in the US working at the intersection of health equity and science represent multiple organizations across various sectors, including government, philanthropic and nonprofit organizations, research institutes, universities, pharmaceutical companies, professional organizations, patient advocacy groups, and CBOs. **Figure 4** summarizes the priorities of these groups along the biomedical research-to-care continuum. An examination of the funding landscape across stakeholder groups found large-scale as well as smaller, focused initiatives. These varied investments are crucial to ensure the widespread integration of health equity approaches within biomedical research and care. **Figure 4** also provides a snapshot of the funding range of *recent* investments across stakeholder groups. In the sections that follow, SPARC surveyed the unique role played by each stakeholder group, their impact on the scientific ecosystem, and current funding mechanisms within the field.

FIGURE 4: Stakeholder Priorities within the Health Equity in Science Ecosystem



Source: Milken Institute (2024)

US Federal Funding

Since 2020, health equity has become a larger priority across government agencies, with significant shifts in how research is conducted and funded. The Department of Health and Human Services (HHS) and agencies within it, such as NIH, have several initiatives spanning critical areas, including diversifying research datasets, capacity building, diverse workforce development, and community engagement. The "Recent Legislation" section in *Health Equity in Science: A Stakeholder and Funding Analysis* outlines recent US federal initiatives impacting health equity in science. Importantly, the majority of recent federal activity has come in the form of Executive Orders rather than legislation, which leaves them vulnerable to being overturned by subsequent administrations. The sections below provide information about selected agencies working at the intersection of health equity and science, focusing on HHS.

Department of Health and Human Services

As the principal federal agency protecting the health of all Americans, HHS oversees numerous offices and agencies aimed at reducing health inequities. Relevant offices and agencies are outlined below in **Table 3**. NIH and FDA have more central roles within this space and are described in the subsequent section.

TABLE 3: HHS Offices and Agencies with Health Equity Initiatives

OFFICE/AGENCY	HEALTH EQUITY INITIATIVES
Office of Minority Health	Enhances the well-being of racial and ethnic minority groups by creating health policies and programs aimed at eliminating health disparities. With a FY2024 budget of $86 million, it offers several funding opportunities to develop health equity leadership, culturally appropriate approaches to reduce disparities, and community-level innovations addressing SDOH.
Office of the National Coordinator for Health Information Technology	Funds health equity research focusing on developing open-source technology and electronic health records to address SDOH. It also supports diverse workforce development by funding MSIs to form consortia and expand public health IT training.
Agency for Healthcare Research and Quality (AHRQ)	Supports research to improve the quality of health care, reduce its costs, and address racial and ethnic disparities in health care. AHRQ also develops tools, training, and resources to translate scientific evidence into practice, helping health systems and clinicians improve care. The SDOH Database provides community-level data for research.
Advanced Research Projects Agency for Health (ARPA-H)	Established in March 2022, ARPA-H accelerates better health outcomes for everyone. Several programs are directly aimed at improvements for those who have been historically underserved and underrepresented in biomedical research.
Centers for Disease Control and Prevention (CDC)	In 2021, CDC launched the CORE Health Equity Strategy to embed diversity, equity, inclusion, accessibility, and belonging into all its operations. In 2023, it published the Health Equity Science Principles, which guide the development and use of health equity science.
Centers for Medicare and Medicaid Services (CMS)	CMS covers more than 160 million people across the US and is critical to ensuring that everyone has access to quality health care. During the 2024 Open Enrollment Period, CMS invested almost $100 million to provide increased enrollment assistance and outreach to underserved communities. CMS has also funded MSIs to conduct research in underserved communities.
Substance Abuse and Mental Health Services Administration (SAMHSA)	Committed to advancing behavioral health equity by promoting accessible mental health services and integrating equity into all its activities. Recent initiatives have focused on addressing SDOH, improving accessibility, developing culturally competent behavioral health professionals, and supporting community-based programs.

Source: Milken Institute (2024)

National Institutes of Health

NIH is the primary federal agency that funds biomedical research through its 27 institutes and centers (ICs) and plays an essential role in advancing health equity in science. In 2010, the NIH established the Office of Minority Programs within the Office of the Director (OD), which eventually became the National Institute on Minority Health and Health Disparities (NIMHD). **Table 4** showcases selected NIH initiatives operating at the intersection of health equity and science.

TABLE 4: Selected Health Equity and Science Initiatives at NIH

IC	DESCRIPTION	
Office of the Director	Many entities within the OD work across NIH to advance health equity. Some are listed below:	
	• Office of Research on Women's Health • Sexual & Gender Minority Research Office • Tribal Health Research Office • Chief Officer for Scientific Workforce Diversity	• UNITE initiative • Artificial Intelligence/ Machine Learning Consortium to Advance Health Equity and Researcher Diversity (AIM-AHEAD) • NIH Common Fund
Office of Science Policy	NIH ENGAGE (Engaging the Public as Partners in Clinical Research) • Aims to incorporate public voices into all phases and types of clinical research. • Working Group includes patients, advocates, researchers, and clinicians.	
All of Us	With the goal of collecting health data from 1 million diverse individuals across the US, a 34 percent budget decrease from $419 million in 2023 to $235 million in 2024 exemplifies the importance of securing stable funding for this program. Budget decreases have delayed the enrollment of a pediatric cohort, and the aim of enrolling 100,000 children has now decreased to only a few hundred.	
NIMHD	NIMHD leads scientific research to improve minority health, reduce health disparities, and promote health equity. The FY2024 NIH budget included $524 million to NIMHD, a slight decrease from 2023.	
NIEHS	NIEHS is committed to reducing environmental health disparities. Key initiatives include: • Climate Change and Human Health • Environmental Health Language Collaborative • Women's Health Awareness Community Engagement Program • Specialized Centers of Excellence on Environmental Health Disparities Research • Partnerships for Environmental Public Health • Data-Informed, Place-Based Community-Engaged Research to Advance Health Equity	

Source: Milken Institute (2024)

Food and Drug Administration

FDA is responsible for the regulatory protection of public health by assuring the safety of drugs, biological products, and medical devices. FDA has a variety of initiatives aimed at advancing health equity in science. In 2022, FDA's Office of Minority Health and Health Equity (OMHHE) allocated more than $8 million to support multiple projects aimed at advancing health equity in regulatory science research and increasing understanding of diverse patient perspectives. The OMHHE Enhance Equity initiative focuses on improving equity in clinical trials by increasing diversity among participants, promoting equitable data collection, and improving communication with diverse stakeholders. In 2023, OMHHE established the Racial and Ethnic Minority Acceleration Consortium for Health Equity (REACH) to enhance research addressing health disparities among racial and ethnic minority populations. In addition, the FDA Office of Women's Health developed the Diverse Women in Clinical Trials Initiative in collaboration with the NIH Office of Research on Women's Health to raise awareness about the participation of women of various ages, races, ethnic backgrounds, and health conditions in clinical trials. As the health equity and science landscape evolves, FDA will remain a key stakeholder in establishing best practices for the equitable development and deployment of drugs and medical technology.

Challenges Related to Federal Government Funding Structures

The challenges related to federal funding described in **Figure 5** are notable, particularly in the current political climate, in which some have taken an offensive stance on DEI initiatives. With some efforts already showing a decline from 2023 to 2024, nongovernment funders have a valuable opportunity to reform funding processes to make them more accessible, flexible, and responsive to the unique needs of health equity initiatives.

FIGURE 5: Federal Funding Challenges for Health Equity

Funding Mechanisms	Funding Restrictions	Administrative Changes
Complex applications are a barrier for smaller organizations with limited administrative resources	Limit ability of grantees to respond to emerging needs	Create inconsistent funding for health equity
Inadequate support for genuine community engagement	Siloed efforts preclude interdisciplinary projects	Undermine long-term efforts
Short-term funding threatens sustainability	Fund matching requirements are a struggle to meet	

Source: Milken Institute (2024)

Philanthropy

Philanthropic organizations are key stakeholders and drivers in advancing health equity in science. Private funders fall into three general categories based on the type and scale of investment. The following sections provide a snapshot. This list is not exhaustive but illustrates the range of funding priorities for these types of philanthropies.

Philanthropic Organizations with Large-Scale Initiatives

Organizations with large-scale initiatives support substantial and/or multiple programs across the health equity in science space, as shown in **Figure 6**. These large philanthropic initiatives are focused on creating lasting change by addressing systemic issues, such as racism and bias, and investing in communities, diverse leaders, climate, social justice, and nutrition. Current funding trends highlight the need for strategies to incorporate health equity throughout the research ecosystem.

FIGURE 6: Snapshot of Priority Areas for Selected Philanthropic Organizations with Large-Scale Initiatives

Organization	CBPR	Community Investing	Data Systems	Health Education	Interdisciplinary Research	Outcomes	SDOH	Systems Change	Technology	Workforce Development
Chan Zuckerberg Initiative		●	●		●			●	●	●
Doris Duke Foundation		●					●	●		●
Ford Foundation		●	●					●	●	●
Kresge Foundation		●					●			
MacArthur Foundation		●	●			●		●		
Rockefeller Foundation										
Robert Wood Johnson Foundation	●	●	●	●	●	●	●	●		●

Source: Milken Institute (2024)

Foundations and Nonprofit Organizations with Focused Initiatives

Overall, the foundations and nonprofits working within health equity have goals to improve the health, education, and financial stability of children and families, emphasizing vulnerable populations. They do this by prioritizing efforts to eliminate health and economic disparities, particularly those affecting communities of color and other marginalized groups. They also invest in global health interventions and innovative technologies to address health inequities in low- and middle-income countries. These foundations and organizations make strategic use of financial resources to promote health equity and support sustainable community development through impact investments and social bonds. In addition, they emphasize health policy reforms, research on health disparities, and improving data systems to inform and drive equitable health outcomes. See **Figure 7** below for a snapshot of priority areas for selected organizations.

FIGURE 7: Snapshot of Priority Areas for Selected Foundations and Nonprofits with Focused Initiatives

Organization	CBPR	Community Investing	Data Systems	Health Education	Interdisciplinary Research	Outcomes	SDOH	Systems Change	Technology	Workforce Development
Annie E. Casey Foundation		●		●		●	●			
Atrius Health Equity Foundation		●					●	●		
Gates Foundation					●	●			●	
California Endowment		●					●	●		●
CDC Foundation		●	●				●			●
Commonwealth Fund				●				●		●
Prebys Foundation		●		●		●		●		
Grantmakers in Health		●		●		●		●		
Kaiser Family Foundation				●			●	●		
Philadelphia Health Partnership		●				●	●			●
Reagan-Udall Foundation for the FDA			●	●				●		●
W.K. Kellogg Foundation		●					●			●

Source: Milken Institute (2024)

CASE STUDY

The Conrad Prebys Foundation

The foundation's mission is to support initiatives that create a more equitable and vibrant community.

In January 2024, the Leaders in Belonging initiative provided five community advocates with unrestricted awards of $100,000 each, highlighting leaders making significant impacts in their communities through cultural connection, health-care access, and youth empowerment.

$10M Strengthening Health Access, Resources, and Excellence (SHARE) Initiative provides two-year, unrestricted grants of up to $250,000 per year to health clinics serving underserved communities.

In May 2024, the foundation announced $6M in grants to 23 local organizations focusing on the mental and emotional well-being of youth and young adults. These grants support various programs, from preventive care strategies to services for diverse groups, including Native Americans, LGBTQ+ youth, and immigrant communities.

Although some foundations are emphasizing more equitable data collection and analysis procedures, larger efforts are needed around this point. To ensure the sustainability of these efforts, there is also an opportunity to increase focus on integrating health equity concepts across the entire research lifecycle. *Health Equity in Science: A Stakeholder and Funding Analysis* provides additional details about selected foundations and nonprofits working in this space.

Research Institutes

Figure 8 shows a snapshot of health equity priorities for selected research institutes. These institutes are largely focused on interdisciplinary and inclusive research collaborations to address health inequities, mentorship, professional development, community-building, inclusive STEM education environments, and patient-centered clinical effectiveness research (see *Health Equity in Science: A Stakeholder and Funding Analysis* for more details). Because these institutes are key to ensuring health equity concepts permeate throughout the research ecosystem, more research institutes should focus on funding health equity efforts to drive impact at scale.

FIGURE 8: Snapshot of Priority Areas for Selected Research Institutes

Organization	CBPR	Community Investing	Data Systems	Health Education	Interdisciplinary Research	Outcomes	SDOH	Systems Change	Technology	Workforce Development
Broad Institute	●		●		●			●		●
Howard Hughes Medical Institute					●					●
Patient-Centered Outcomes Research Institute	●			●	●	●				

Source: Milken Institute (2024)

University Initiatives

Academia provides integral research that forms the foundation of our understanding of health inequities and allows us to build evidence-based strategies for mitigating them. Many HBCUs and other MSIs are at the forefront of addressing health disparities in terms of expertise but have historically lacked adequate funding. Since 2021, federal agencies, private foundations, and philanthropic organizations have increasingly recognized the importance of supporting these institutions. However, while some MSIs have seen increases in health equity research funding, certain challenges persist. These include the need for long-term, sustainable funding to ensure ongoing research and program implementation. Investment is also needed to enhance the research capacity at these institutions to manage and utilize the funds effectively. Additionally, ensuring equitable funding distribution to a diverse range of institutions, including smaller and less visible MSIs, remains a significant barrier. Additional detail on these and other university initiatives is provided in *Health Equity in Science: A Stakeholder and Funding Analysis*.

Pharmaceutical Companies

Pharmaceutical companies play a crucial role in health equity initiatives due to their comprehensive involvement in the health-care ecosystem, spanning drug development, clinical trials, and medication adherence programs. Their extensive reach enables them to address inequities by ensuring that new drugs and treatments are accessible to diverse populations, promoting inclusive clinical trials, and supporting initiatives that enhance health-care delivery in underserved communities. During the COVID-19 pandemic, pharmaceutical companies highlighted their ability to rapidly develop vaccines and treatments, focusing on susceptible populations and addressing systemic vulnerabilities in developed nations. By prioritizing health equity as both a moral and business imperative, these companies can embed equitable practices throughout the product lifecycle, significantly impacting global health outcomes. Additional details on these and medical tech firms can be found in *Health Equity in Science: A Stakeholder and Funding Analysis*.

Community-Based Organizations

Many CBOs are on the frontlines of addressing health disparities and operate at the intersection of equity and research to improve health outcomes for their communities. Their focus areas include training and technical assistance, policy advocacy, research, and community outreach and accessibility. **Table 7** in *Health Equity in Science: A Stakeholder and Funding Analysis* highlights several CBOs that participate in research and focus on data equity. While CBOs cover a broad range of areas relevant to health equity, there is less emphasis on mental health services tailored to marginalized communities. Furthermore, few organizations explicitly address the intersectional health disparities experienced by individuals who belong to multiple marginalized groups, such as LGBTQIA+ individuals within racial minority communities. Additionally, while digital literacy is a focus, there is less effort to bridge the digital divide by providing access to technology and training. Addressing these gaps through increased funding would enhance the impact of CBOs working toward achieving health equity.

Cross-Sectoral Partnerships

Broad, systemic goals such as achieving health equity require interdisciplinary approaches and cross-sector partnerships to be successful. Organizations are increasingly understanding this and building coalitions, alliances, networks, and collaborations to tackle the major barriers to health equity. **Table 5** shows several significant cross-sectoral partnerships. Together, these groups are working to enhance data sharing, community-driven research efforts, equity in clinical research and practice, and STEMM workforce diversity.

TABLE 5: Selected Cross-Sectoral Partnerships

PARTNERSHIP	DESCRIPTION
All In: Data for Community Health	A nationwide coalition of organizations and practitioners invested in advancing health equity through multisector data sharing. It involves health-care providers, government agencies, community organizations, and others.
Civic Science Fellows Program	Established in 2020, this program is designed to bridge the gap between science and society by embedding emerging leaders in specific organizations. It aims to foster a culture of civic science where research is deeply integrated with community engagement and societal needs.
Encoding Equity in Clinical Research & Practice	In June 2024, the Council of Medical Specialty Societies announced this alliance, supported by a $3 million grant from the Doris Duke Foundation. The alliance aims to rethink the use of race in clinical algorithms by ensuring they reflect unbiased evidence to improve patient outcomes.
STEMM Opportunity Alliance	In May 2024, this multi-stakeholder initiative released a National Strategy for STEMM Equity and Excellence with the goal of helping 20 million people from historically excluded communities thrive in STEMM fields—across all jobs and sectors—by 2050. They aim to invest $15 billion in research infrastructure and capacity building at HBCUs, TCUs, and other MSIs by 2040.
Together for CHANGE™	This initiative promotes health equity in Black communities across the US, with a focus on improving the STEM talent pipeline. Meharry Medical College and Regeneron partnered with AstraZeneca, Novo Nordisk, and Roche as founders of this multimillion-dollar effort, which is led by the Diaspora Human Genomics Institute.

Source: Milken Institute (2024)

Other Key Stakeholders

Additional stakeholders essential to advancing health equity from research to care include health-care systems, health insurance companies, policymakers, legislators, and community members. *Health Equity in Science: A Stakeholder and Funding Analysis* provides details on these groups.

Overall, those individuals directly impacted by health inequities are the primary stakeholders. Their lived experiences provide invaluable insights that can significantly inform health equity initiatives. By actively engaging these communities in the research planning, implementation, and evaluation stages, we can ensure that findings and initiatives are timely, relevant, and tailored to those most affected.

CROSS-CUTTING OPPORTUNITIES FOR PHILANTHROPIC SUPPORT

Nationwide, health disparities are significant, enduring, and growing, largely due to obstacles embedded throughout various societal systems. Health equity involves enhancing opportunities for everyone to achieve their best possible health, regardless of identity, location, or income. Scientific research is pivotal in advancing health equity by providing the evidence necessary to understand and address health inequities. As described in this guide, there are several significant barriers to integrating health equity into scientific research. Underfunding of diverse research areas, a lack of workforce diversity, and minimal community involvement have created data gaps, biases, and outcomes that fail to address health disparities, all of which must be tackled to advance health equity.

The pursuit of transformative solutions can be facilitated by philanthropic support for initiatives that bring together interdisciplinary teams, foster collaborations across sectors, and advance community-centered research. **The Milken Institute SPARC has identified five opportunities where philanthropic investment is uniquely poised to support work that accelerates action around health equity research to impact care and health.** As **Figure 9** shows, most of the opportunities are focused on community engagement and empowerment, capacity building and workforce development, research innovation and data equity, and systemic change and amplification—areas where funding gaps persist. Specific approaches for each opportunity are included on the left and expanded upon below.

FIGURE 9: Cross-Cutting Opportunities for Philanthropic Funding to Drive Impact

		IMPACT			
		Community Engagement & Empowerment	Capacity Building & Workforce Development	Research Innovation & Data Equity	Systemic Change & Amplification
OPPORTUNITY 1 Build Community-Centered Research Systems	Establish Digital Health Technology Hubs for Equitable Outcomes	✓	✓	✓	
	Network Community-Led Research to Build Sustainable Pathways	✓	✓	✓	✓
	Support Community Navigators Linking Community and Research	✓	✓	✓	✓
	Invest in Community to Address Social Determinants of Health	✓	✓		✓
OPPORTUNITY 2 Expand Efforts and Collaboration—Scale Up and Create Robust Networks	Build a Comprehensive Health Equity Resource Database	✓	✓	✓	✓
	Form a Health Equity in Science Funders Consortium	✓		✓	✓
	Fund Interdisciplinary and Implementation Research Partnerships with MSIs	✓	✓	✓	
OPPORTUNITY 3 Train a Diverse and Interdisciplinary Workforce	Bring Diverse Computational and AI Expertise to Biomedical Research	✓	✓	✓	
	Expand Educational and Career Programs and Training in Interdisciplinary Methods	✓	✓		✓
OPPORTUNITY 4 Catalyze Transformative Health Equity Research for Effective Implementation and Care	Prioritize Equity-Driven Molecular Medicine and Care-Focused Research	✓	✓	✓	✓
	Elevate Health Equity Champions to Break Down Barriers and Foster Inclusive Research	✓	✓	✓	✓
OPPORTUNITY 5 Measure Impact and Emphasize Continuous Improvement	Develop a System of Evidence-Based Practices, Strategies, and Tools to Reliably Measure Outcomes	✓			✓

Source: Milken Institute (2024)

Philanthropic Opportunity 1: Build Community-Centered Research Systems

Building community-centered research systems is crucial for health equity because it ensures that the voices and needs of those most affected by health disparities are directly integrated into the research process. This approach fosters trust, relevance, and cultural competence in research, leading to more effective and sustainable health interventions. Ultimately, community-centered research empowers communities to take an active role in shaping health solutions, creating a more equitable and inclusive health-care landscape for all. **Philanthropy is well-suited to support community-centered research systems because it can provide flexible, long-term funding that enables innovative, community-driven approaches to health equity. Additionally, philanthropic organizations can serve as connectors, bringing together diverse stakeholders to collaboratively address complex health challenges. Our analysis revealed that the following four approaches would have significant impacts.**

Establish Digital Health Technology Hubs for Equitable Outcomes

With technology and AI being central to addressing key health issues, it is vital to flip the script when it comes to problem-solving, starting with asking communities where the problems lie. Research funders, universities, and the tech industry should seek out partnerships with communities to learn what health issues they need help with and co-develop technology-based solutions around these.

Philanthropy is well-poised to support innovative approaches and partnerships to develop a plan for establishing digital health technology hubs, with the goal of equitably accelerating health innovation. The hubs would provide communities with a forum for raising concerns while matching them with researchers who can help co-design solution-focused research and technology. The platform would provide researchers and communities with data, technology, and cross-disciplinary training opportunities. These hubs could also network existing efforts to develop comprehensive, standardized datasets for shared use. As part of a future endeavor, hubs like this could be integrated into learning health systems to bring additional community insight and technological innovation to these teams and evidence-based care to communities.

Network Community-Led Research to Build Sustainable Pathways

Community organizations are central to focusing research efforts on community needs, yet these groups typically require more research expertise and sustained funding to carry out research projects. This is especially problematic for marginalized communities whose needs are often overlooked or excluded from academic research.

Community-led research often addresses complex, systemic issues that require long-term engagement and solutions. Connecting community organizations can empower different groups to share resources and join forces, making research more impactful and leading to more sustained

efforts. Philanthropic funding can be leveraged to establish a network of community organizations conducting health equity-focused research to build capacity. Sustained funding for building this type of network is lacking from other sources; thereby, philanthropy has an opportunity to bolster capacity building for CBOs. This network could provide training opportunities for organizations to grow their research practices, share data, and diversify their funding sources to provide more sustainable, long-term support. Networking these groups would also help them strengthen their approaches by sharing best practices, learnings, and resources, building awareness of potential funders and partners, boosting fundraising efforts, and developing compelling research proposals. This network could also lead to the development of more longitudinal, proactive studies, which can have an outsized impact on health equity.

Support Community Navigators Linking Community and Research

Community navigators are crucial in driving forward community-centered research systems in ways that eliminate health inequities. They are vital agents for trust and relationship building, outreach and dissemination efforts, resource sharing, and combating misinformation. Thus, these individuals are essential for bringing communities into research and translating research back to communities. Recent budget cuts to NIH's *All of Us* Research Program have affected funding for these community navigator roles, cleaving hard-won bonds between communities and the research ecosystem. The cuts hit frontline staff at community outreach and engagement organizations the hardest, with an estimated 600 of 3,000 full-time positions affected. In addition to creating significant setbacks for the program, these cuts also draw attention to the need to support these roles more generally. It is especially critical not to lose the ground gained by all the time, resources, and effort *All of Us* has invested in building trust with traditionally marginalized communities through funding community navigator roles.

Supporting community navigators is a clear gap where philanthropic funding can play a significant role. As federal funding for community navigators lapses, philanthropy has an opportunity to protect these investments and enhance or scale them up as appropriate. More specifically, to support the ongoing mission of *All of Us* and the 21st Century Cures Act, foundations and philanthropic organizations could join forces and directly fund core professionals at front-line organizations so that they can continue the work of engaging with community members and connecting them to research efforts. This joint initiative could enhance existing community navigator networks, build on the current model by working with organizations to identify future opportunities for nongovernment funding, and develop robust impact metrics and reports to demonstrate the efficacy of these programs. Funding this type of initiative would support the crucial role of community navigators in trust-building, improved health literacy, and increased education. It would also enable the continuation of one of the most significant research efforts to enhance health equity through science.

This effort will require collaborative philanthropic engagement to not only fill in the gap from federal funding cuts but also enhance and scale up community navigator networks. Funders could focus on supporting organizations local to their foundation or invite proposals from groups that

need community navigator funding. There is room for broad participation in an effort like this, with many opportunities for small and large philanthropic investments to support a wide range of organizations at varying levels.

Invest in Community to Address Social Determinants of Health

Many communities across the US suffer from historic underinvestment and economic instability, particularly communities of color and rural populations. This significantly impacts their health, affecting housing, employment, education, and health-care access. This economic isolation also means that these communities are less likely to be involved in research efforts. Targeted investments are needed to address these disparities and promote health equity.

Utilizing strategies such as trust-based philanthropy and impact investing targeted to small nonprofits and CBOs in marginalized populations can improve economic opportunity and address disparities in SDOH. Trust-based philanthropy provides grantees with multi-year, unrestricted funding, and impact investing prioritizes social and environmental outcomes over financial returns. These funding mechanisms allow greater flexibility for CBOs to innovate and sustain programs without the constant pressure of fundraising. Blending these approaches can address short-term funding challenges while supporting systemic, equitable change. By leveraging the strengths of trust-based philanthropy and impact investing, funders can create a significant and lasting impact on marginalized communities, promoting economic stability and health equity.

Philanthropic Opportunity 2: Expand Efforts and Collaboration—Scale Up and Create Robust Networks

Small and fragmented efforts to improve health equity, while well-intentioned, often lack the scale and influence needed to drive meaningful change in health equity. By scaling up initiatives and creating robust networks, we can leverage collective expertise, resources, and innovation to develop more comprehensive and sustainable solutions that address health disparities on a systemic level. This not only amplifies impact but also ensures that advancements in health equity reach more communities, particularly those most marginalized. **Philanthropy has a crucial role in magnifying and unifying these efforts by providing the necessary infrastructure, fostering collaboration, and supporting the development of scalable, community-driven solutions. Through strategic investments, philanthropy can help bridge gaps, break down silos, and create a more coordinated approach to advance health equity, as outlined in the three approaches below.**

Build a Comprehensive Health Equity Resource Database

The scores of current health equity initiatives and organizations that operate in the US need greater connection around their common goal. Many initiatives and organizations are working toward addressing health equity with no overarching resources to guide and connect them. Without a shared system, these efforts risk being overlooked, duplicative, and inefficient, potentially competing with one another for funding and visibility and repeating mistakes where lessons could have been shared.

Philanthropy can catalyze the building of a comprehensive, AI-enabled database of health equity initiatives that would connect various groups so that they can share resources, knowledge, best practices, and even data, as appropriate. The database could also provide resources for community action boards, patient advocacy groups, and interdisciplinary training. A significant piece of this effort should include a focused strategy and investment for dissemination so that individuals are aware of and utilize the database.

A unified platform would connect disparate efforts, fostering collaboration and partnerships across different organizations and sectors. Centralizing information and resources would make it easier for stakeholders to access relevant data, tools, and support. Raising awareness of existing initiatives and resources could attract more attention and funding to health equity efforts. A comprehensive database could also help identify gaps in current efforts and direct resources to areas of greatest need. The platform would facilitate data-driven decision-making, enhancing the impact and effectiveness of health equity programs. In addition, it would help programs hone their focus areas, making them more effective at tackling specified problems. Furthermore, it could lead to larger joint initiatives that leverage the strengths of diverse stakeholders to develop more comprehensive solutions to health equity challenges. Finally, building this resource to be an AI-enabled database would save time and resources and be a positive catalyst for the field.

Form a Health Equity in Science Funders Consortium

The fragmented funding landscape for incorporating health equity into scientific research has led to duplicated efforts and inefficient resource allocation. Aligning these siloed efforts under a single consortium would enable funders to:

- Pool resources and coordinate funding efforts, creating synergies and maximizing the impact of investments.
- Facilitate knowledge sharing and collaboration among funders, researchers, and community organizations.
- Invest in capacity building through grants, training programs, and infrastructure development, empowering under-resourced communities to participate fully in the research process.
- Engage in advocacy to promote policies that support health equity in science, such as funding reforms, interdisciplinary collaboration, and a focus on SDOH.
- Develop and implement standardized evaluation frameworks, ensuring progress is effectively measured and reported and strategies are continuously improved.
- Promote diversity, equity, inclusion, and justice in the grantmaking process by, for example, standardizing grant applications and offering feedback on rejected proposals.

There is a significant opportunity for an established philanthropic organization to form a funders consortium focused on implementing the activities outlined above. These activities would address

a wide range of barriers within the scientific ecosystem that present challenges to advancing health equity. The expected goals of the consortium should be focused on fostering a scientific landscape where health equity is a fundamental principle, driving research, practice, and policy. The Health Equity in Science Funders Consortium would drive impact by leveraging the strengths and resources of multiple organizations, reducing duplication of efforts, and ensuring that funds are used effectively. Additionally, the consortium could ensure that research and funding efforts prioritize the needs of the most underserved communities and encourage new approaches to solving complex health equity challenges.

Fund Interdisciplinary and Implementation Research Partnerships with MSIs

MSIs are underfunded but central to promoting equity in biomedical research and care. HBCUs and other MSIs, such as HSIs and TCUs, are fundamental to addressing health inequities from the perspective of lived experience but have historically lacked adequate research funding and resources. Along with more direct funding to support research and science education—from study to dissemination—these institutions would benefit from sustained, strategic resource-sharing as well as genuine partnerships to build capacity, engage with communities, and advance interdisciplinary and implementation research.

There is a significant opportunity for philanthropic funding to scale up existing partnerships with MSIs and model them to build other successful collaborations. Partnerships to consider scaling up or modeling include the Meharry-Vanderbilt Alliance to end health disparities via a bolstered education pipeline, and the Morehouse and Harvard Partnership in Neuroscience Growth to strengthen research and educational collaborations at the two institutions. Creating public-private partnerships between larger, more established organizations and smaller organizations leverages each one's unique strengths. Funding additional partnerships such as these would be transformative because true partnerships are where diversity, equity, and inclusion intersect. Holistic efforts cannot be accomplished through siloed approaches. Moreover, focusing on interdisciplinary and implementation research would incentivize the bringing together of more diverse perspectives and expertise—within and across institutions—to identify innovative solutions for tackling complex health inequities. It would also encourage researchers to work more broadly, preparing them to communicate and collaborate across disciplines. Such efforts present a united front when advocating for future changes to foster health equity.

Philanthropic Opportunity 3: Train a Diverse and Interdisciplinary Workforce

The underrepresentation of diverse voices in health science has resulted in gaps in research and care. Traditional approaches often lack the cultural competence and interdisciplinary insights necessary to fully grasp the complexities of health disparities. By building a workforce that mirrors the diversity of the communities served and encouraging collaboration across disciplines, we can ensure that health research and interventions are more inclusive, effective, and responsive to the unique challenges faced by different groups, ultimately driving greater equity in health outcomes.

The Milken Institute's previous report on *The Value of Building an Interdisciplinary Scientific Workforce — A Call to Philanthropy* explores how philanthropy can promote interdisciplinary science and foster innovation and collaboration. **Philanthropy is uniquely positioned to drive progress in health equity by funding innovative training programs and initiatives that build a diverse and interdisciplinary workforce. Its ability to invest in long-term, transformative solutions makes it a powerful catalyst for creating a more equitable and inclusive health-care ecosystem.**

Bring Diverse Computational and AI Expertise to Biomedical Research

Biomedical research increasingly involves large, complex datasets, such as genomic sequences, imaging data, and EHRs. Analyzing and interpreting these datasets requires advanced computational skills often lacking in traditional biomedical research teams due to gaps in training and education programs. Research teams also often lack representation of diverse individuals with this advanced computational expertise. Therefore, in addition to the need for more advanced computational training, there is also a need for better representation of marginalized groups working in these areas to inform the application of computational approaches, including AI models, which will lead to effective findings for the broader population.

Bringing more diverse perspectives with computational expertise to biomedical research will significantly shape the field's evolution, accelerating progress through more diverse, equitable, and inclusive analytics. By working with nonprofits that specialize in supporting underrepresented students in tech, philanthropy can create partnerships to train the next generation of diverse biomedical researchers in computational methods, emphasizing the use of these approaches to advance health equity. See the Milken Institute's *Transformative Computational Biology Giving Smarter Guide* for more information about related philanthropic opportunities.

Expand Educational and Career Programs and Training in Interdisciplinary Methods

The underrepresentation of diverse groups in science, technology, engineering, arts, mathematics, and medicine (STEAMM) restricts innovation, biases research and development, perpetuates health and social inequities, and limits economic and educational opportunities. Addressing this underrepresentation is crucial for realizing the full potential of STEAMM disciplines and ensuring that their benefits are accessible to all segments of society. Efforts to broaden access to STEAMM education and increase recruitment and retention of underrepresented groups have been ongoing for decades. There are many existing training programs and initiatives to enhance diversity in this workforce. These efforts work along the entire educational and workforce pipeline and include targeted youth outreach, recruitment strategies in underrepresented communities, online programs, alternative learning paths to accommodate different life circumstances, scholarships, financial aid, and mentorship programs at the undergraduate, graduate, and postdoctoral stages. While these efforts can be very effective at increasing recruitment, there are significant challenges to retaining diverse populations in the STEAMM workforce in the form of systemic barriers, resource limitations, workplace culture, and lack of program sustainability.

Philanthropic funding is uniquely poised to develop a STEAMM Diversity Network that pulls together existing initiatives with the goal of advancing diversity in STEAMM fields to achieve better health outcomes. The network would allow for resource and opportunity sharing, collaborative projects, mentorship programs across institutions, convenings, advocacy, and community building. Specifically, it could provide much-needed opportunities for cross-disciplinary training and collaborative spaces to explore interdisciplinary projects, driving future research and initiatives. Moreover, by centering itself around interprofessional training that combines knowledge across fields (such as biology, the social sciences, computer science, etc.), the network would give participants the necessary training to enact organizational change to improve outcomes.

By leveraging their different networks, existing programs have the potential to bring together greater numbers of students and can build upon their program structures to support training across STEAMM fields. They can also partner to provide new professional development opportunities for students looking to explore more interdisciplinary avenues. Philanthropy has the flexibility and adaptability necessary to support this type of endeavor, which will require room to iterate as various partners join and contribute to shaping the program. Pulling together programs spanning educational and workforce training will reinforce pipelines by broadening support and opportunities for underrepresented groups. Furthermore, centering the initiative on training to build strong, multidisciplinary problem-solvers will equip future leaders with the tools and perspective necessary to tackle ongoing issues in health equity.

Philanthropic Opportunity 4: Catalyze Transformative Health Equity Research for Effective Implementation and Care

Historical underrepresentation of marginalized communities in health research has led to biased findings and solutions that fail to address the unique challenges faced by these populations. Traditional research models often overlook or inadequately address the SDOH that contribute to disparities, resulting in interventions that are less effective or even harmful for certain groups. Incentivizing transformative health equity research that uses innovative approaches that better reflect the diverse needs of all populations can eliminate long-standing health inequities.

Philanthropy can catalyze and drive a shift toward more inclusive, community-centered research approaches that accelerate the development and implementation of research that advances equitable care on a broader scale. Further, its ability to invest in innovative, high-risk, and high-impact projects makes philanthropy a key force in shaping a more just and equitable health landscape. Philanthropic organizations can also amplify impact and drive sustainable change toward health equity, especially as other funders and sectors are pressured to move away from this critical area.

Prioritize Equity-Driven Molecular Medicine and Care-Focused Research

The lack of emphasis on health equity within molecular medical research yields outcomes that do not always apply to diverse groups. Additionally, the preoccupation with molecular approaches has impeded the effective investigation of questions that could yield more immediate improvements in health and health care, particularly for populations historically excluded from medical research. To combat these issues, more funding should be oriented toward (1) molecular research with a clear health equity component and (2) research for care, implementation, and prevention.

Philanthropic organizations have the flexibility to support more studies focused on accelerating the implementation of findings, especially because there is a significant gap in research on these topics. For example:

- Studies expanding genomic research to include diverse populations by conducting large-scale genome-wide association studies (GWAS) and whole-genome sequencing in underrepresented racial and ethnic groups to identify genetic variants that affect disease risk and drug response.
- Studies on the political and commercial determinants of health, an area of rising concern that has received little funding from other sources, even though they are central to health equity.
- Studies that employ CBPR to develop culturally tailored interventions that integrate genetic, environmental, and social determinants of health.

Support for these types of studies could be accomplished through a grant program or innovation competition, which would incentivize interdisciplinary collaboration and prioritize projects that address the most pressing needs of marginalized communities. By fostering partnerships between researchers, community organizations, and health-care providers, these initiatives can help bridge the gap between molecular research and practical, real-world applications. Funding that incentivizes high-risk, high-reward projects, can also lead to the creation of scalable and sustainable interventions that significantly improve health outcomes for underserved communities. Moreover, these programs would not only drive innovation in equitable health solutions but also ensure that the benefits of scientific advances are more broadly distributed, raise awareness of health equity issues, influence policy changes, and empower communities to take an active role in shaping their health, ultimately contributing to a more just and inclusive health-care landscape.

Elevate Health Equity Champions to Break Down Barriers and Foster Inclusive Research

In the wake of recent Supreme Court decisions affecting affirmative action and a general decrease in backing for DEI initiatives, there is an urgent need for more support to highlight and elevate researchers and organizations already conducting exemplary work within health equity. Many researchers focused on health disparities—especially those from marginalized communities—face significant barriers, including being discounted or overlooked for funding in favor of nonexperts

whose work may not be rooted in lived experience or community-engaged approaches. This misalignment often results in essential, equity-focused research being underfunded or ignored. By elevating individuals who have demonstrated dedication to health equity research, we can shine a light on those who are making a substantial impact despite these challenges. Such attention would serve as a counterbalance in a climate where broader discrimination and systemic biases continue to undermine progress. This recognition could also help counteract the diminishing focus on DEI efforts and encourage a greater influx of diverse talent, fresh ideas, and funding into the field.

One effective strategy for elevating these voices is through targeted recognition and support, such as awards with monetary prizes. Awards would not only validate and raise the profile of health disparities experts but also provide critical resources and motivation for continuing their research. Award programs focused on health equity in science can also help inspire future generations to pick up the torch and focus on these critical issues. Philanthropic organizations can play a transformative role by helping to fill critical gaps where traditional funding sources fall short and fostering a research landscape that truly reflects and serves diverse communities. Philanthropy is also an ideal funding source due to its flexibility, mission-driven focus, and independence from market and political pressures.

Philanthropic Opportunity 5: Measure Impact and Emphasize Continuous Improvement

Persistent disparities and inconsistencies in health outcomes across different populations reveal the limitations of current measurement methods. Without standardized, evidence-based practices, it is difficult to accurately assess progress, identify effective interventions, and ensure accountability in efforts to achieve health equity. Developing reliable tools and strategies is essential to bridge these gaps and drive meaningful, data-informed improvements in health outcomes for all communities. **Philanthropy can provide the flexible, long-term funding needed to innovate and refine evaluation methods. Philanthropic organizations are uniquely positioned to take risks and invest in pioneering approaches that may not yet attract traditional funding sources. By supporting the creation of reliable measurement systems, philanthropy can drive more effective, impactful interventions in health equity, ensuring that resources are used wisely, and outcomes are truly equitable.**

Develop a System of Evidence-Based Practices, Strategies, and Tools to Reliably Measure Outcomes

From budding initiatives to established efforts, many organizations involved in research lack strategies to guide the development and implementation of health equity initiatives and tools to measure the various impacts of their work. While many organizations use health equity-related metrics, tracking is usually done on an inconsistent, ad hoc basis, and reporting is primarily internal. To truly advance health equity from research to care, initiatives need to be united by:

- a clear set of organizational strategies and best practices (that can be customized for different types of institutions)
- implementation of evidence-based research and care practices
- standardized metrics and indicators for measuring impact and tracking progress
- standards for reporting to enhance transparency and accountability

Philanthropy can rely on its flexible funding mechanisms and diverse stakeholder network to build a strategic approach for implementing health equity initiatives, including impact metrics and reporting standards. A key component of this initiative would include assembling a working group of expert stakeholders from various sectors and disciplines to design the unified approach, starting with a comprehensive needs assessment to identify gaps and strengths, weaknesses, opportunities, and threats. This could be followed by constructing a detailed plan consisting of a strategic framework and best practices to guide the various organizations involved. The working group could also develop standardized metrics and indicators to measure impact and evaluate progress consistently. Reporting infrastructure will be important to support communication and dissemination efforts, which are crucial for ensuring transparency and accountability across organizations. In addition, organizations will need funding for training and capacity building to support the implementation of the strategic framework. Along these lines, the effort will require regular monitoring and evaluation to ensure adherence and continuing improvement.

An investment like this could lead to significant improvements in health outcomes for marginalized populations, reduce health disparities, and generate cost savings for biomedical research and health-care systems. Additionally, organizations that adopt these evaluation strategies would enhance their reputation and credibility as leaders in health equity, setting a standard for others to follow and creating scalable models that can be applied widely to promote health equity nationally and globally.

Government agencies such as NIH, FDA, and CDC and professional organizations such as the American Society of Human Genetics have individual strategic plans to advance health equity. Uniting these under a common approach designed to work across scientific areas and organizations would strengthen these efforts and provide a starting framework for new organizations. It would also establish a common ground to begin conversations with corporations and nonprofit organizations working directly with communities. Research institutes could incorporate workforce development aims and patient experience to create a more unified approach. Similarly, involving universities with large medical and public health schools with existing health equity initiatives could create training opportunities around developing and implementing these strategies and tools. Finally, support from larger philanthropic organizations would bring expertise in implementation as well as credibility and influence to this effort.

CONCLUSION

Health equity ensures that everyone has a fair opportunity to achieve their highest level of health. It is an ethical imperative that reflects a commitment to justice and the dignity of all individuals. The COVID-19 pandemic and 2020 social justice movements magnified ongoing, systemic inequities that lead to poor health outcomes for marginalized groups. Now, with mounting shifts away from DEI endeavors, we are in a critical period for maintaining momentum and fostering continuing progress.

Rigorous research and data analysis help identify the root causes of health inequities, whether they stem from socioeconomic factors, environmental conditions, or systemic biases, for example. Research, especially when conducted in line with the needs of marginalized communities, develops new treatments and approaches to reduce disparities and bias. Innovations in medical research and technology, such as genomics, AI, and telemedicine, offer new tools to tailor interventions and improve access to quality care for underserved populations. Furthermore, science informs policy development and public health strategies, ensuring they are grounded in empirical evidence. By fostering a deeper understanding of health determinants and outcomes, science enables the development of more inclusive health-care practices and policies, ultimately driving progress toward a more equitable health system for all.

To overcome emerging challenges and the persistent systemic barriers driving health inequities, key stakeholders must individually and collectively strive to enhance health outcomes and reduce disparities. Across disciplines and sectors—including academia, industry, health care, government, and nonprofits—bold leaders serve integral roles in paving the way for achieving health equity. Many cross-sector collaborations are being formed, signaling that decision-makers understand the need for enhanced connections around common goals. While federal funders are primarily focusing on making the research enterprise more equitable, some philanthropic organizations and corporations are focusing on supporting communities. Philanthropy can combine and bridge these efforts to achieve more holistic solutions that bring research and community together.

Philanthropic capital can be strategically and deftly deployed, spurring action across the health equity and science ecosystem and overcoming obstacles to progress. By acting on one or several opportunities identified in this guide, philanthropists can drive large-scale initiatives and collaborations that combine resources and brainpower to enact broad changes. Strong collaborations will help grow and sustain the health equity in science space, leading to transformative discoveries that allow people from all backgrounds to thrive. With its ability to convene diverse stakeholders and drive solutions, philanthropy plays a pivotal role in accelerating equitable health research by providing the necessary funding for initiatives that challenge biases and prioritize inclusion. To truly achieve health equity for all, there is an urgent need for progress that moves us forward collectively.

APPENDIX

Missing Data Needed to Achieve Health Equity

Certain types of data are essential to meaningfully achieve health equity, yet they are often missing or inadequately captured in current research and clinical databases. **Table 6** outlines the types of data that are crucial for promoting health equity and the areas where data are frequently lacking.

TABLE 6: Important Data Types for Health Equity and Associated Gaps

DATA TYPE	SIGNIFICANCE	CURRENT GAPS
Behavioral Health Data	Information on lifestyle choices, mental health, and substance use is critical for developing targeted interventions aimed at preventing and treating health issues.	These data are often under-collected because of the stigma associated with mental health and substance use disorders, as well as privacy concerns.
Disability Data	Information on disabilities is essential for assessing health service accessibility and tailoring interventions to meet the needs of individuals with disabilities.	Data on the type and extent of disabilities are often not detailed enough or are inconsistently collected across health systems.
Diverse Genetic, Genomic, and Biological Data	Genetic and other biological data can help understand and predict differential susceptibility to diseases as well as responses to pharmacogenetic and other treatments among populations. Many researchers are transitioning from genetics to genomics, which considers the interaction between genes and the environment to address health equity more comprehensively.	There is a significant lack of genetic data from non-European populations, which limits understanding and increases the risk of health inequities. The development of tools, such as diagnostics and reference standards recognized by FDA is limited by the type and quantity of data being collected.
Geographic Data	Information on patients' community and environmental conditions can indicate health risks associated with certain locations, such as pollution or lack of access to care.	Detailed geographic data are rarely linked to individual health records, limiting the ability to perform precise spatial health analyses.
Health Services Utilization Data	Understanding how different populations access and utilize health-care services can help to identify barriers to care.	Comprehensive utilization data, especially disaggregated by key demographics, are often not available, limiting the ability to design effective system interventions.

Language and Cultural Data	Data on patients' primary language and cultural background can guide the development of culturally sensitive research and clinical care practices.	Such data are rarely collected systematically, yet they are critical for ensuring that communication and interventions are effective across diverse cultural groups.
Race and Ethnicity Data	This type of data is crucial for identifying and analyzing health disparities among different racial and ethnic groups.	While many health systems collect race and ethnicity data, inconsistencies in how these data are categorized and reported can lead to underestimations of disparities. Moreover, these data are often not detailed enough to capture the diversity within broad racial and ethnic categories.
Socioeconomic Data	Income, education level, employment status, and living conditions profoundly impact health outcomes. Collecting this type of data helps identify how social and economic disadvantages contribute to health disparities.	Comprehensive and consistently collected socioeconomic data across health-care settings are often lacking. There is also a need for this data to be integrated with health records to facilitate more holistic health assessments and interventions.

Source: Milken Institute (2024)

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