Introduction

The lessons of the civil rights movement of the 1950s and 1960s continue to shed new light on the modern-day inequities and disparities within our health care, educational, financial, economic, and public policy systems. Systemic disparities—coupled with a history of discriminatory health research and care practices such as the US Public Health Services Syphilis Study at Tuskegee, the use of Henrietta Lacks’ cells without her permission in medical research, and ongoing modern-day examples—have created mistrust in and barriers to health care and participation in clinical research among underserved communities. The COVID-19 pandemic laid bare inequities that have been decades, if not centuries, in the making.

The Biden Administration has made equity a central priority in the US. Beginning with Executive Order 13985 on “Advancing Racial Equity and Support for Underserved Communities Through the Federal Government” to the Office of Management and Budget report “Study to Identify Methods to Assess Equity” and beyond, this priority is apparent in the spirit and conduct of federal business, hiring, and policy. By defining equity¹ and underserved communities,² the Biden Administration set a vocabulary for a common vision of opportunity and justice nationwide.

The Milken Institute is driving a focus on diversity and representation within biomedical research by issuing publications such as "Achieving Health Equity" and the first Policy Issue Brief in this series, "A Call to Action for Diversity in Clinical Trials." Further, FasterCures and the National Civil Rights Museum in Memphis, Tennessee, convened leaders in biomedical research, community-based organizations, and health care, together with local...
and national policy stakeholders to discuss lessons from the past to the present, and to define rigorous solutions to ensure that a more equitable future is implemented across the health and biomedical research ecosystem. This event focused on health as a civil right, linking social and economic mobility, public policies, financial investments, and education access as vital components in building equitable, unbiased health care and biomedical research.

A central pillar of this event was the direct, lived experience of people working to improve the health of Memphians. For context, Shelby County in Tennessee suffers from several key health disparities, according to BlueCross BlueShield of Tennessee and the Shelby County Health Department³:

- **2x**
  - Black individuals in Shelby County are at least twice as likely as White individuals to die from heart disease, diabetes, stroke, homicide, or HIV.

- **2x**
  - Infant mortality is twice as high in Black populations as it is in White populations.

- **3x**
  - New rates of HIV cases are three times higher in Shelby County compared to the rest of the state.

- **2x**
  - Twice as many people in Shelby County experience violent crime compared to the rest of the state.

- **50 years**
  - Wealth disparity has not changed in 50 years, with median income in Black households only 58 percent that of White households.

To address health equity, we must embed it into our policies and business models, with practical solutions for eliminating inequities that exacerbate health disparities. Forum participants learned from national and “boots on the ground” efforts that value communities’ expertise and involve them in decision-making to prioritize and improve community and individual health outcomes. The forum highlighted lessons learned at the community, local, and national levels; and identified tactics and priorities tested in communities that build equity locally and can serve as models for other regions in the US.
### Key Issue: Partnerships

**From the Biden Administration’s Executive Order 13985: “The head of each agency shall evaluate opportunities, consistent with applicable law, to increase coordination, communication, and engagement with community-based organizations and civil rights organizations.”**

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<tr>
<th>Structural Barrier</th>
<th>Building trust can be difficult, and populations from underserved and historically excluded communities often mistrust health and research systems, which may further exacerbate inequity.</th>
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| **Key Insights**   | - Marginalized communities must be included in the conversation to address health equity, yet they cannot bear the entire burden of improving problems that they did not create.  
- A joint task force on COVID-19 for Memphis, Shelby County, and surrounding areas included representatives from the municipalities as well as hospitals, public and private school systems, public health departments, and local leaders. These representatives worked diligently to negotiate and compromise on policies, and in the process improved the health of their communities and built long-lasting relationships that could influence approaches to other common health problems.  
- Formal partnerships, research and program grant funding, or community sponsorships often require screening mechanisms and/or application processes, yet due diligence and metrics traditionally used in these processes can be inequitable. |
| **Recommendations for Action** | - Engage with partners across the community—from parking-lot attendants to administrators at information desks to local business leaders—to support culturally significant institutions and thereby create a natural bridge to increased representation of underserved populations in clinical research and care.  
- Rally broad support, and link health equity priorities to incentives to achieve common goals, which could help new and existing community and health-care and research stakeholder partners to reach common ground on difficult issues.  
- Reevaluate traditional application criteria and processes, which tend to be difficult or impossible for community organizations to meet, to ensure that the needs and value of all organizations entering the partnership are equitably reflected. |
### Key Issue: Data Sharing

From the Federal Equitable Data Working Group’s “A Vision for Equitable Data”: “Equitable data are those that allow for rigorous assessment of the extent to which government programs and policies yield consistently fair, just, and impartial treatment of all individuals. Equitable data illuminate opportunities for targeted actions that will result in demonstrably improved outcomes for underserved communities.”

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<th>Structural Barrier</th>
<th>Information about the health of individuals in underserved communities is often siloed within each organization they interact with. The quality of this information reflects the policies and practices under which it was collected.</th>
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| Key Insights       | • Data are a currency that brings together organizations and identifies areas requiring the most work.  
                        • In Memphis until the mid-2000s, all births and deaths were recorded on color-coded paper cards to differentiate race. This is just one example that underscores how some policies were built and still stand on inequitable or outdated infrastructures that create true barriers to reliable data collection as well as to health care for community members.  
                        • A financial barrier to improving health-care services and health outcomes for the long term arises when health-care systems do not successfully run programs that demonstrably improve health and therefore keep people from reentering the health-care system. This cycle drives down the health-care system's source of revenue and lessens resources for future programs.  
                        • States should be encouraged to accept more funding for Medicaid. Disparities in screening for and diagnosis of early-stage disease are demonstrably greater in states that did not accept Medicaid expansion. In addition, Medicaid funding and the data sharing it promotes help to sustain more programs. |
| Recommendations for Action | • Share data among health organizations outside the context of a community health needs assessment to sustain funding for successful health promotion programs.  
                        • Share data to help leverage funding for health equity programs and policies, and scale efforts to test the impact of those programs in underserved and historically excluded populations. |
## Key Issue: Workforce Diversity for Health Care and Research

The 117th Congress's American Rescue Plan Act of 2021 allocated funding to help expand and diversify the US health-care workforce and provides scholarships and loan repayments for people working with underserved communities.

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<th>Structural Barrier</th>
<th>The health-care and clinical research workforce does not yet reflect the diversity of the people it serves.</th>
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### Key Insights

- To truly diversify the health and research workforce, cultural competency training should be required, students should be expected to train using unbiased approaches, and students from marginalized communities should be prioritized and provided opportunities for career advancement.
- The health research career pipeline should begin before the medical school recruitment process. Although important workforce initiatives exist, a seamless pipeline approach is needed to diversify the clinical research and health-care workforce.
- Community health-care centers, minority-serving academic institutions, local university campuses and school systems, and faith-based community organizations could partner to create programs to educate and advance career opportunities for youth interested in medicine and health care who lack access, such as those growing up in inner cities or rural communities. One example of such a partnership in Memphis is a cooperative agreement linking the University of Memphis, Meharry Medical College, Methodist Le Bonheur Healthcare, and Church Health. Partnership programs may also provide financial support to students to attend medical school and/or to care providers to practice in their own communities, where a diverse health workforce may be of the greatest need.

### Recommendations for Action

- Expand funding and grants for programs such as loan repayments to help recruit more students from historically excluded communities into the workforce, as well as encourage all students to care for people in these communities.
- Formalize partnerships to create a systemic approach that, over time, can address workforce diversity and inequity.
- Develop novel approaches to sustainable workforce pipeline approaches. For example, Okunsola's Community Doula Training at the Jamaa Birth Village in St. Louis, Missouri, provides pre- and postpartum doulas with stable health-care jobs. Scalable models could be replicated to develop training and education programs to increase workforce diversity to impact the health of the community directly and expand the expertise of diverse providers.
# Key Issue: Accountability

From the Biden Administration’s Executive Order 13985: “The Director of the Office of Management and Budget (OMB) shall, in partnership with the heads of agencies, study methods for assessing whether agency policies and actions create or exacerbate barriers to full and equal participation by all eligible individuals.”

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<th>Efforts to achieve health equity must embed accountability mechanisms, including rigorous evaluation with standardized metrics.</th>
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| Key Insights       | • Data infrastructure improvements, such as robust electronic health record systems or other data-collection methods, coupled with investments in health system infrastructure, can support measurement of the quality of services provided.  
                      • Sustained system improvements to eliminate the barriers to equitable data collection enable local public health departments to coordinate and collaborate better with other health-care leaders in their communities. This collaboration, in turn, could allow for more robust systems-level evaluation of interventions to study its impact on those improvements.  
                      • Ensuring that community-based organizations have the resources and infrastructure needed to evaluate health outcomes and impact of health equity efforts has been a key challenge. The right expertise, coupled with lived experience, and technology are critical for systematically collecting data.  
                      • Data points and metrics should be used to amplify progress, for example by sharing objective data combined with storytelling approaches to create human-centered reporting. |
| Recommendations for Action | • Make funding contingent on a solid evaluation plan employing metrics that are agreed upon and aligned across partnerships.  
                                • View financial and economic investment through the lens of both community benefit and impact as incentives to address inequities, particularly to eliminate the barriers to accessing and receiving high-quality health care.  
                                • Document and share best practices and programmatic evaluations with context so that others can build on the lessons learned. Further, financial investment and incentives should be viewed as both "carrot" and "stick" methods.  
                                • Ensure the role of public-private partnerships is critical in creating sustainable funding mechanisms and ensuring mutual accountability.  
                                  • The need exists for measurable qualitative and quantitative goals to determine what interventions reduce health disparities and inequities in improving health outcomes and aligning financial incentives.  
                                  • Partnerships should leverage equitable data-driven approaches, including data sharing across programs and local health systems, to ensure that achieving health equity is a standard process. |
Conclusion

The first-ever convening of the FasterCures Health Equity Forum revealed several key factors that support the implementation and practice of health equity into systematic processes and procedures. The forum provided expert thought leadership and highlighted case studies from lived and learned experiences at the local and community levels, as well as the executive leadership level. The forum also identified strategies to drive actionable policy change and bridge the gaps that perpetuate inequities within our health systems, with a focus on patient and community needs. A tour of the National Civil Rights Museum at the Lorraine Motel helped to remind us of the civil rights movement's historical impact on health care and public policy. As we move forward, a focus on implementing the identified strategies to address systemic inequities is critical to achieving lasting change for the populations suffering the greatest disparities across the country.

About Us

About the Milken Institute

The Milken Institute is a nonprofit, nonpartisan think tank. For the past three decades, the Milken Institute has served as a catalyst for practical, scalable solutions to global challenges by connecting human, financial, and educational resources to those who need them. Guided by a conviction that the best ideas, under-resourced, cannot succeed, we conduct research and analysis and convene top experts, innovators, and influencers from different backgrounds and competing viewpoints. We leverage this expertise and insight to construct programs and policy initiatives. These activities are designed to help people build meaningful lives in which they can experience health and well-being, pursue effective education and gainful employment, and access the resources required to create ever-expanding opportunities for themselves and their broader communities.

About FasterCures

FasterCures, a center of the Milken Institute, is working to build a system that is effective, efficient, and driven by a clear vision: patient needs above all else. We believe that transformative and lifesaving science should be fully realized and deliver better treatments to the people who need them.

About the Center for Public Health

The Milken Institute Center for Public Health develops research, programs, and initiatives designed to envision and activate sustainable solutions leading to better health for individuals and communities worldwide.
About the Authors

Yasmeen Long is a director at FasterCures, a center of the Milken Institute. Her expertise lies within health equity, disparities, outcomes, policy, clinical research, patient engagement, and social determinants of health. Before joining FasterCures, Long served as the codirector of the Health Policy Fellowships and Leadership Programs at the National Academy of Medicine. These fellowships were designed for early- to mid-career national and international health-science scholars. She also served as a program officer at the Patient-Centered Outcomes Research Institute (PCORI), where she designed strategic objectives to advance patient and stakeholder engagement in patient-centered outcomes research. At PCORI, Long built key relationships with academic researchers, health-care providers, patient advocates, and policy stakeholders. Prior to PCORI, she directed global health policy programs in the US, Asia, and the Middle East at the Johns Hopkins Bloomberg School of Public Health in collaboration with the Bloomberg Philanthropies and the World Health Organization. She holds an MA in sociology and women's health from Suffolk University and a BSc in health sciences from Howard University.

Amanda Wagner Gee is an associate director at FasterCures, working on projects related to health equity and diversity in clinical trials and community-based research infrastructure. Her expertise is in areas related to clinical and preclinical research design and conduct. Prior to joining FasterCures, she worked at the National Academies on the Forum for Drug Discovery, Development, and Translation on projects related to the clinical trials enterprise, diversity and inclusion in clinical trials, real-world data and real-world evidence, and patient- and participant-engagement. She began her career as a research scientist working on drug discovery with the Harvard Stem Cell Institute and the National Center for Advancing Translational Sciences at the National Institutes of Health. She received her master's degree in cell biology from Duke University.

Athena Rae Roesler is an associate director at the Milken Institute Center for Public Health. Her work champions and evaluates public-health policies, solutions, and partnerships to build a more equitable world. Most recently, she led a partnership with the DC government to understand better how cities can leverage food procurement to support nutrition, the environment, and equitable local economies. Roesler’s experience in public health started literally from the ground up, teaching thousands of students about nutrition as a farm-based educator in Arizona, Washington, DC, and South India. Her graduate research centered on the human right to food, a dignified emergency food system, and strategies to reduce health disparities. She was part of a research team evaluating California’s sugary drink tax and warning label policies. At Leah’s Pantry, a nonprofit supporting California SNAP-Ed, she furthered behavioral economics-based and trauma-informed nutrition security initiatives. Roesler holds a Master of Public Health in public health nutrition from the University of California, Berkeley and a BA in public health and educational studies from American University.

Endnotes

1. Executive Order 13985 defines equity as “the consistent and systematic fair, just, and impartial treatment of all individuals.”

2. Executive Order 13985 defines underserved communities as “populations sharing a particular characteristic that have been systematically denied a full opportunity to participate in aspects of economic, social, and civic life.”