

The ABIM Foundation hosted its annual Forum in August 2020, in a meeting whose virtual format and agenda were heavily influenced by the COVID-19 pandemic. For the third consecutive year, the Forum focused on issues of trust. This year's discussion centered on the severe health equity challenges that the pandemic—and its disproportionate impact on people of color—made starkly visible.

Introducing the Topic

Richard Baron, MD, the president and CEO of the American Board of Internal Medicine and the ABIM Foundation, began the meeting by recalling the heated 19th century debate that led to the adoption of the 'germ theory' of disease, and noting how COVID-19 has shown us that the theory offers a true but insufficient explanation of how diseases spread. He said that the Forum would offer an opportunity for participants to think together about "how the impact of COVID can be understood through the lens of earned mistrust, and how we might together develop strategies to earn trust back." He then asked the group for a moment of silence in honor of COVID's victims, those who have suffered from police violence, and Representative John Lewis.

Christine Sinsky, MD, an ABIM Foundation Trustee and the chair of the Forum Planning Committee, called for a shared understanding that "inequity leads to mistrust, and the way to improve trust is not to ask the mistrustful to change but to look at and address the root causes of mistrust." She introduced a video that described many ways in which COVID had taken a disproportionate toll on Black and brown communities.

Drs. Baron and Sinsky then discussed the inequities that COVID has highlighted. Dr. Baron said he found, alongside these disturbing inequities, some cause for optimism about medicine's opportunities to do better. "Something that gives me hope is that empathy is so critical to what we do that anyone in patient care has to have had some experience thinking about what it's like to be in their patients' shoes," he said. "Recognizing discrimination is a way of developing empathy," Dr. Sinsky added.

Patient Stories

Forum participants heard from patients on both days. On the first day, Denise Octavia Smith, survivor of a rare kidney disease and the founding Executive Director of the National Association of Community Health Workers, shared her story. Ms. Smith said the clinicians who cared for her in Connecticut did not know about a course of treatment that she said was common in neighboring New York, and described winding up in the emergency room 7–9 times a year for seven years. She faulted her clinicians for neither asking about the impact of her illness on her family nor helping her understand her condition. For example, she became pregnant during this time even though, unbeknownst to her, pregnancy causes her condition to worsen. When she asked her physician why he had not explained this to her, she said he replied that he "knew that black women love to have babies." She described how a patient navigator working with her ultimately helped her find the care she needed in Manhattan.

In reflecting on her experience, Ms. Smith said that "we have a lot of work to do, and COVID-19 has highlighted and brought urgency to our opportunity for real transformation." She called on Forum participants to remember that health systems were not designed for people who looked like her, noting that "if we don't remember how

the system was built, we can't address disparities." She also called for clinicians to be attentive and responsive to the patients in front of them, suggesting that if her own clinicians had taken the time to talk with her about her goals and her condition, her experience would not have been so negative. Finally, she urged clinicians to remind themselves regularly about why they got into this work: to improve well-being.

On the second day, Kellan Baker, MPH, MA, Centennial Scholar at the Johns Hopkins Bloomberg School of Public Health, shared his story of relating to the health care system as a transgender man. "In the midst of a global pandemic, it's hard not to think about dying," Baker began, before saying that when he dies, he wants to be cremated because he does not trust anyone to handle his body with respect.

He described his experience in seeking gender-affirming care in 2005, when he said the message he received from doctors was 'we don't know what to do with you and we won't help you'. He said that although much has changed since, physicians still convey a lack of understanding, and for many, a lack of interest in gaining it. He said that many practices have told him that they don't see "people like me" and that a fertility practice that did agree to provide care told him to come after hours so as not to upset the women being treated there.

He talked about how he benefits from his privilege as a white man with health insurance in his efforts to obtain care, but said that he doesn't trust anyone he meets in health care settings. Meanwhile, he said that for transgender people without privilege, health care is "not just unpleasant – it can be a nightmare." He told the story of a black transgender woman in Washington, DC who was involved in an accident and died after paramedics mocked her and delayed her ability to receive care; an expert witness in a wrongful death suit her family brought testified that she had an 85 percent chance of survival with timely and proper care.

"Repairing breaches of trust must start with providers recognizing my humanity and recognizing the responsibility to treat us as human beings," he said. He recommended that providers think about where transgender people "fit" in their practice; for example, he said hormone therapy can be managed in primary care practices. He also said clinicians and office staff would benefit from cultural competency training about the care of transgender people. Finally, he recommended collecting data on sexual identity and using that data to inform practice and quality of care.

Clinicians' Perspectives

On the Forum's first day, five people who had been involved in delivering care during the pandemic shared their reflections about trust and health equity. The session began with a video that featured highlights from remarks the panelists had recorded before the meeting. Moderator Jackie Judd, the chair of the ABIM Foundation Board of Trustees, then asked them about their experience.

"We have systems implemented for disasters but there wasn't anything in place for something like a pandemic."

- Andres Maldonado, MD

"We have systems implemented for disasters but there wasn't anything in place for something like a pandemic," said Andres Maldonado, MD, a resident in New York City who had COVID. However, he said that the experience as a COVID patient had enabled him to connect with patients on a deeper level.

Kate Walsh, MPH, the President and CEO of Boston Medical Center (BMC), emphasized the importance of restoring clinician trust. She noted that the CDC's changing guidance on PPE during the pandemic's early stages had an understandably damaging impact on clinician trust. She said BMC attempted to provide as much information as possible as a remedy for mistrust, but she was uncertain about the success of that approach.

Marcus Henderson, MSN, RN, a Lecturer and Clinical Instructor at the University of Pennsylvania School of Nursing, said that the pandemic had reinforced the importance of community-based work. "The key to addressing disparities is understanding the issues that community members are facing," he said. "Sometimes we need to stop looking at the textbook or the Power Point and see people and communities for who they are." He stressed the need for clinicians to recognize their biases and build empathy.

Geneva Tatem, MD, the Fellowship Program Director at Henry Ford Hospital, discussed the importance of persuading individuals from underserved populations to participate in clinical trials, particularly for a COVID vaccine. She stressed the need to understand these patients' justified mistrust about medical research, and to approach them with a level of humility to build trust. She also noted the need for investigators who come from underserved communities.

Adam Sharp, MD, MSc, a research scientist and emergency medicine physician at Kaiser Permanente, said clinicians need to have "uncomfortable conversations" and display greater transparency in order to build trust. He proposed looking outside the health system for novel strategies to bring people of color into positions of influence, and to collaborate with community organizations as equal partners to address patients' social needs.

Understanding Inequity: the Kimball Lecture

David Williams, PHD, the Florence & Laura Norman Professor of Public Health at Harvard University, delivered this year's Kimball Lecture by video before the meeting. He began his remarks by offering data about the racial disparity in U.S. deaths from COVID-19, with Blacks dying at 2.3 times the rate of whites. He then detailed the extreme differences in income and wealth between African Americans and whites, with Blacks earning only 59 percent of whites' annual income (unchanged since 1978) and possessing 10 percent of their wealth. He noted the link between these economic circumstances and the greater rate of COVID infection among African Americans, who disproportionately work in lower-paying jobs that they cannot perform from home.

Dr. Williams then distinguished between individual and institutional discrimination, with residential segregation as a highly consequential form of the latter. He traced the many consequences of residential segregation, such as poorer schools and fewer jobs, and argued that these inequities do not reflect a broken system, but rather "a carefully crafted system functioning as intended, successfully implementing social policies, many of which are rooted in racism."

Dr. Williams discussed the health impact of living with worse air pollution, greater exposure to the deaths of loved ones, and the stress of discrimination. He spoke about the Everyday Discrimination scale, which he helped create and which seeks to measure what he called the "small indignities" that people of color often bear, such as rudeness, poor service, and invoking unjustified fear in others. He said studies have linked higher scores on the scale with higher rates of illness like breast cancer and type 2 diabetes. He also noted that police shootings of unarmed Blacks—but not armed Blacks—have been shown to decrease mental health across the entire local Black population.

He said that taken together, these various differential effects lead to a phenomenon sometimes called accelerated aging. At the same chronological age, African Americans are 7.5–10 years "older" with regard to their health, with earlier onset of conditions such as hypertension and diabetes. Here too he drew a link with COVID, noting a study that showed that 88 percent of those hospitalized with the disease in New York City had two or more co-morbidities.

To address this set of problems, Dr. Williams called for creating "communities of opportunity to minimize, neutralize and dismantle the systems of racism that create inequities in health." His solutions included investing more heavily in early childhood, increasing taxes and governmental transfers to reduce child poverty, increasing the minimum wage, and promoting marriage.

Within health care, he said that we must eliminate inequities in the receipt of high value care and build trust to improve patient-provider relationships and quality. He described the causes of mistrust (e.g., misinformation, historical injustice) and its consequences (e.g., lower utilization of high quality care, lower adherence, poorer

management of conditions, lower likelihood of good relationships with providers). He noted that mistrust is not only interpersonal but also includes mistrust of institutions and systems, and characterized mistrust as both a social determinant of health and a "protective response" against interlocking and systemic inequities.

He noted a study of people living with HIV that found no racial disparities for patients whose providers had high cultural competence. In addition to cultural competence, he stressed the need for structural competence, with clinicians paying attention not only to implicit bias but to how bias has shaped how our institutions function.

"There have...been few other cases in the history of civilized peoples where human suffering has been viewed with such peculiar indifference."

- W.E.B. DuBois

Dr. Williams closed his remarks with a reflection on empathy and the bias in favor of members of one's own group seen worldwide. He quoted W.E.B. DuBois' description of the indifference of white Americans toward the health of Black people: "There have...been few other cases in the history of civilized peoples where human suffering has been viewed with such peculiar indifference." He called for a sustained focus on raising awareness of inequities and building empathy.

During the Forum, Foundation CEO Richard Baron, MD and Dr. Williams engaged in a conversation. Dr. Williams commented that the students he has taught at elite universities knew very little about embedded racial disparities in American life, and described research findings that the population subgroup most likely to underestimate existing degrees of inequity in wealth and education were highly educated whites who "believe in a just world."

Dr. Baron invited Dr. Williams to offer advice to the health care leaders in attendance. Dr. Williams called for individual physicians to demonstrate creativity in addressing inequity, citing examples of physicians writing "prescriptions" for food or helping create medical-legal partnerships that worked with patients on issues such as unhealthy living conditions. He also discussed the importance of advocating for health care institutions to use their community benefit dollars to advance equity and pointed to the Healthcare Anchor Network, a collaboration of health care systems seeking to help build more inclusive and sustainable local communities.

When asked for suggestions for improving empathy, Dr. Williams stressed the research findings that humans have ingrained bias by age 10 and suggested promoting greater cross-racial interaction among young people. He also cited the importance of individuation in our view of people, as opposed to the social categorization that comes naturally. Overall, however, he said improving empathy is a very challenging task, and called for more research about how to tell the story of the challenges faced by disfavored populations in a way that produces empathy.

Seeking Solutions: Learning/Action Sessions

Participants met in 21 small groups over the meeting's two days in an attempt to develop bold, actionable ideas that could help deliver a more equitable health system. They explored topics related to medical education and training, research, clinical practice, public health and particular populations such as incarcerated people and Native Americans. Some of their specific ideas were:

Workforce Diversity: Improve the diversity of the health care workforce through collaborations between academic medical centers and community partners to increase interest in health careers and readiness to pursue them among members of minority groups, beginning at the K-12 level

Workforce Training: Create "Introduction to Racial Empathy" course for all faculty and trainees, incorporating virtual reality training on implicit bias, empathy, and effective patient advocacy, and include a research component to identify most successful elements

Community/Patient Engagement in Health Research: Found an independent community ethics/research review board to establish guidance around COVID-19 testing and research, reviewing proposed research and generating innovative research ideas based on community priorities, with possible application beyond COVID-19

Patient and Workforce Safety: Treat inequity as a category of harm, embedding equity into existing patient safety efforts and adopting successful strategies from the patient safety movement

Telemedicine and Digital Health: Deliver 50 percent of a health system's care virtually, training health care professionals to provide effective virtual care and ensuring equity and access to care across the patient population

Primary Care and "Healthy Communities": Create "Healthy Communities" structures that support partnering of primary care groups with communities, specialists, hospitals, public health and other sectors to identify local health needs and meet them collectively

Primary Care Global Contracting: Provide for primary care through a global contract that pays for health rather than for services delivered, an approach that has been demonstrated to reduce health disparities

Building Trust for COVID Vaccination: Public and private payers and clinical organizations calculate data on clinical risks for COVID morbidity/mortality at level of census tracts, and trusted community organizations lead outreach efforts to promote vaccination in those communities

Strengthen Public Health: Improve the health of communities by better equipping and supporting public health to play a central role, including presenting a vision for funding of public health and rebuilding of the CDC, a proposed legislative agenda, and partnerships between public health advocacy groups and disease-specific advocacy groups

Public Health Approaches to Gun Violence: Launch a community-by-community dialogue to "reframe" the discussion about firearm injury prevention, with communities developing substantive plans for preventing firearm injuries through the implementation of evidence-based interventions

Incarcerated Transition Program: Improve transition of care for released prisoners from correctional health systems to community health systems by hiring community health workers with histories of incarceration

Critiquing the Solutions: Funder Reactions

Leaders from organizations that fund health care research offered reactions to the concepts from the small group sessions. Moderator Elizabeth McGlynn, PhD, Vice President for Kaiser Permanente Research, moderated the session, and began by noting common themes among the groups related to the use of data and measures, infrastructure and new ways of looking at the workforce.

Holly Humphrey, MD, President of the Josiah Macy, Jr. Foundation, commented on the groups that focused on medical education and the health workforce. She related their work to Dr. Williams' discussion of creating communities of opportunity, such as by starting at the K-12 level to create a pipeline of medical students. She also drew a connection between the discussions of empathy at the Forum and the idea of using virtual reality as a tool to explore racism and close the empathy gap; she said she wondered whether it could be applied beyond medical education to the nation as a whole.

Nathaniel Stinson, PhD, Director of the Division of Scientific Programs at the National Institute on Minority Health and Health Disparities, said he was struck by the small groups' interest in working at the community level. He talked about his own experience working on a Navajo reservation, where leaders made progress in increasing car seat usage and reducing auto injuries after consulting with tribal women and discovering the importance they placed in swaddling infants. This consultation led to the idea of making slip covers for car seats that were made of traditional materials. "There are people out there who know better than we know about what matters for their health," Dr. Stinson said. "They may not have degrees but we need to listen to them."

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Laurie Zephyrin, MD, MPH, MBA, Vice President, Health Care Delivery System Reform at the Commonwealth Fund, cited cross-cutting themes about re-imagining health systems and engaging communities. Arlene Bierman, MD, MS, the Director of the Center for Evidence and Practice Improvement at the Agency for Healthcare Research and Quality, noted the importance of listening to the community, developing sustainable programs, and building the evidence base for scalable interventions to achieve health equity. She cautioned participants about the significance of paying explicit attention to equity in performance improvement work, as efforts to improve quality and safety can sometimes exacerbate inequity.

Don Schwarz, MD, Senior Vice President at the Robert Wood Johnson Foundation, spoke about the difference and occasional tension in public health between local private and public actions and national policy action, and commented about the small groups' efforts to navigate this tension. He suggested ways to bridge national and local elements, such as appealing to both nationally and locally-focused philanthropic organizations, and enlisting groups like the American Heart and Lung Associations and the American Cancer Society, which have one foot in local communities and the other in national efforts.

Daniel Yang, MD, a Program Officer at the Gordon and Betty Moore Foundation, noted the changed climate in which the groups were developing these ideas. Rather than engaging in pilot testing of new concepts, he said, the urgency of COVID and the changes it has prompted both enable and require testing ideas at a larger scale. For example, he said, the increase in virtual care offers an opportunity to rethink how we provide in-person care as well, and could also offer fertile ground for potential partnerships between health systems, technology companies and others to improve virtual care.

Reflections

Both Forum sessions concluded with reflections. Lisa Cooper, MD, MPH, Bloomberg Distinguished Professor at the Johns Hopkins University School of Medicine, offered remarks on the first day. She emphasized Dr. Williams' focus on institutional and structural racism and their impact, and his argument that mistrust is a protective response on the part of members of communities that have suffered from racism. She also noted his call for creating "communities of opportunity" and raising awareness of inequity, building the scientific case demonstrating inequity and emphasizing empathy. She noted that empathy was also a common theme of the health system representatives who spoke.

Dr. Cooper's other takeaways from the day included how compassion, fairness, humility and transparent communication increase trustworthiness, how self-awareness and familiarity increase empathy, the importance of acting collectively, and the need for clinicians to invite their patients to speak and ask questions and to listen respectfully without judgment, not only to patients but also to community partners. She noted that one of the meeting participants stated the following: "Our crisis is actually a communications problem because we don't hear as much as we think we do."

Dr. Cooper called for collective action with community partners, those working in public health and the broader

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society. She said it was critical for health systems to commit to eliminating disparities, and said a lack of clarity about their commitment sows doubts in communities. She also stressed the importance of relationship-centered care and structural competency in solving the equity problems we face.

Don Berwick, MD, MPH, President Emeritus and Senior Fellow at the Institute for Healthcare Improvement, spoke on the Forum's second day. Dr. Berwick said he came to the meeting with a question: Why have we known for so long about the equity issues affecting our health system but done so little to address them? He said he found some answers to that question in Dr. Williams' lecture. He also noted Kellan Baker's characterization of physicians as saying 'We don't know what to do with you and we won't help you' and suggested that that kind of rejection was "fundamental not just for LGBTQ people but other balls we've been dropping."

Dr. Berwick noted the traditional tension between governmental and non-governmental action, along with that between national and local action. He suggested, however, that national action is required to address the chronic, and in some cases worsening, conditions facing poorer Americans. He argued that these conditions are a policy problem related directly to a lack of equitable redistribution policies at the national level.

"We have discomfort about 'politicizing health care'," he said. "I think we need to get over it. David Williams provides evidence of the need to dismantle structures of privilege and power, which requires that those with the most resources help those who have the least."

Dr. Berwick returned to the issue of trust, and emphasized that "trust can't withstand inauthenticity." He said restoring and keeping trust requires making progress on the inequities that we have accommodated for so long, and recommended that the health care community focus on criminal justice reform.

Conclusion

Richard Baron ended the meeting with a reference to a historian's observation that the Black Death made the Renaissance possible by creating conditions under which people were willing to think differently. He asked if COVID could offer a similar opportunity. If so, he said, taking advantage will require Forum participants to act as advocates for change at their institutions. He added that the ABIM Foundation was committed to supporting the group in their efforts.

