2020 ABIM FOUNDATION FORUM BUILDING TRUST & HEALTH EQUITY DURING COVID-19

# Background Paper

By Timothy Lynch, JD

The ABIM Foundation has focused on the issue of trust at its annual Forum for the past two years. In 2018, participants explored why and how trust affects the health care system. In 2019, they took a closer look at specific ways to enhance trust across a variety of relationships in health care. The Foundation was in the midst of preparing for a 2020 Forum devoted to the relationship between trust and the inequities that persist in our health care system when the COVID-19 pandemic struck. This horrible pandemic has laid bare the disproportionate way that Americans of different races and backgrounds experience a health crisis and its aftershocks, and has shaken public trust in the ability of our health care system and our institutions to deliver care effectively and equitably. The subsequent killing of George Floyd, and the protests that followed it, have put structural racism and inequities in criminal justice into even sharper focus, along with social and economic policies that affect housing, education, transportation and access to quality health care and mental health.

During this first online Forum, participants will consider issues of trust and equity through the lens of the pandemic. They will explore what our continuing experience with COVID-19 has taught us about the extent to which a lack of trust is both a cause and effect of inequity, and whether and how creating trust can help produce a fairer system.

Issues of trust and equity are at the heart of medical professionalism, as it is defined in the Physician Charter that guides the ABIM Foundation's work. The Charter includes three fundamental principles that underlie medical professionalism. The first two are patient welfare and patient autonomy, which can be exercised only in the context of trusting relationships. The Charter says that professionalism is the basis of medicine's contract with society, and states: "Essential to this contract is public trust in physicians, which depends on the integrity of both individual physicians and the whole profession."<sup>1</sup> The Charter's third fundamental principle is social justice. Here, the Charter calls for physicians to "work actively to eliminate discrimination in health care, whether based on race, gender, socioeconomic status, ethnicity, religion, or any other social category."

Forum participants will work collaboratively with leading experts in areas such as workforce diversity, research bias, practice inequities and social determinants of health to develop and refine innovative actions related to trust and equity that could help address the inequities that have long existed and have manifested themselves even more starkly throughout this crisis. This paper will provide a brief overview of some of the equity concerns that COVID-19 has raised, and background information about some of our experts' areas of focus.

<sup>1</sup> ABIM Foundation, American College of Physicians, European Federation of Internal Medicine. The physician charter [Pamphlet]. Philadelphia: 2002. Available from: http://abimfoundation.org/what-we-do/physician-charter.

## **COVID-19 and Equity**

Although COVID-19 has affected all Americans, its consequences have fallen disproportionately on African-Americans, Hispanics, Native Americans and other members of low-resourced communities. According to data collected by the Centers for Disease Control and Johns Hopkins, though African Americans represent 13 percent of the US population, they represent 33 percent of those hospitalized with COVID-19.<sup>2</sup> Across the country, African Americans have died at a rate of 50.3 per 100,000 people, compared with 20.7 for whites.<sup>3</sup> In Michigan, which is 14 percent African-American, 40 percent of the dead are Black.<sup>4</sup>

Hispanics have also borne a heavy burden. In New York City, the initial epicenter of the pandemic in the U.S., death rates for African-Americans (92.3 deaths per 100,000 population) and Hispanics (74.3) were significantly higher than death rates for white (45.2) or Asian (34.5) people.<sup>5</sup> The elevated death rate among Hispanics is particularly striking because, while elderly Americans have been disproportionately vulnerable to COVID-19, the U.S. Latino population is younger than other groups. In California, statistics released by the state in late April showed that Latinos made up 64.9 percent of COVID-19 deaths among the 18–49 population (which is 43.5 percent Latino overall) and African Americans accounted for 15.3 percent of the deaths in that age group while comprising only 6.3 percent of the overall population.<sup>6</sup>

Meanwhile, the Navajo Nation had the second-highest

Although COVID-19 has affected all Americans, its consequences have fallen disproportionately on African-Americans, Hispanics, Native Americans and other members of lowresourced communities.

infection rate in the U.S. as of mid-May, trailing only New York.<sup>7</sup> A lack of clean running water in many households was a potential contributor to the outbreak.<sup>8</sup> Tracking Native American infection rates has been made difficult by flaws in state reporting; although most states have reported infection data by race, nearly half are simply categorizing COVID infections striking Native Americans within the "other" category.<sup>9</sup>

- 2 Aubrey A. Who's Hit Hardest By COVID-19? Why Obesity, Stress And Race All Matter. NPR [Internet]. 2020 Apr 18; Available from: https://www.npr.org/sections/health-shots/2020/04/18/835563340/whos-hit-hardest-by-covid-19-why-obesity-stress-and-race-all-matter
- 3 Pilkington E. Black Americans Dying of COVID-19 at Three Times the Rate of White People. The Guardian [Internet]. 2020 May 20. Available from: https://www.theguardian.com/world/2020/may/20/black-americans-death-rate-covid-19-coronavirus.
- 4 Laughland A, Zanolli L. Why is Coronavirus Taking Such a Deadly Toll on Black Americans? The Guardian [Internet]. 2020 Apr 25; Available from https://www.theguardian.com/world/2020/apr/25/coronavirus-racial-disparities-african-americans?CMP=share\_btn\_tw
- 5 Centers for Disease Control and Prevention. COVID-19 in Racial and Ethnic Minority Groups. https://www.cdc.gov/coronavirus/ 2019-ncov/need-extra-precautions/racial-ethnic-minorities.html
- 6 Cowan J. Why Covid-19 Is Deadlier for Black and Latino Californians. New York Times [Internet]. 2020 Apr 28; Available from: https://www.nytimes.com/2020/04/28/us/coronavirus-california-black-latinos.html
- 7 Morales L. Coronavirus Infections Continue to Rise on Navajo Nation. NPR [Internet]. 2020 May 11; Available from: https://www.npr.org/sections/coronavirus-live-updates/2020/05/11/854157898/coronavirus-infections-continue-to-rise-on-navajo-nation
- 8 Morales L. Navajo Nation Sees High Rate of COVID-19 and Contact Tracing Is a Challenge. NPR [Internet]. 2020 Apr 24; Available from: https://www.npr.org/2020/04/24/842945050/navajo-nation-sees-high-rate-of-covid-19-and-contact-tracing-is-a-challenge
- 9 Nagle R. Native Americans Being Left Out of US Coronavirus Data and Labelled as 'Other.' The Guardian [Internet]. 2020 Apr 24; Available from: https://www.theguardian.com/us-news/2020/apr/24/us-native-americans-left-out-coronavirus-data

Experts have offered a number of social, economic and health-based explanations for the racial, ethnic and income-based disparities we have seen in COVID-19 outcomes:

- a higher prevalence among African Americans than whites of underlying conditions, such as high blood pressure, heart disease and diabetes, that are known to be associated with worse outcomes from COVID-19;
- a much greater likelihood that low-income workers (a group that includes disproportionate numbers of members of minority populations) have continued to work through the pandemic in frontline jobs that cannot be performed remotely (e.g., retail employees, delivery people, sanitation workers) according to the U.S. Bureau of Labor Statistics, less than 20 percent of Black workers and only about 16 percent of Hispanic workers are able to telecommute;<sup>10</sup>
- reduced access to care due to lower health insurance rates among Hispanics and African Americans (Hispanics are almost three times more likely to be uninsured than whites, and African Americans are almost twice as likely<sup>11</sup>), exacerbated by the refusal of a number of states with heavily African-American populations to expand Medicaid under the Affordable Care Act;
- greater reliance on public transportation and likelihood of living in more overcrowded/ multigenerational housing arrangements among low-income Americans; and,
- individuals from racial and ethnic minority groups are over-represented in jails, prisons and detention centers, which have seen high incidences of the coronavirus.

A study by Amfar, the Foundation for AIDS Research, found that social determinants, not underlying health conditions, were the primary factors causing a higher rate of illness and death among African Americans. These social factors included employment (surprisingly, counties that had both disproportionately high Black populations and high unemployment rates actually had fewer coronavirus cases, shedding light on the significance of Black Americans' likelihood of working in "essential" jobs that made social distancing impossible<sup>12</sup>), as well as access to health insurance and medical care and poor air and water quality.

Members of vulnerable populations are expected to face continuing challenges as Americans continue to address COVID-19 and its social and economic after-effects. These include increased difficulty accessing testing and treatment due to insurance status and other barriers to accessing care, and bearing the brunt of the economic harms that the pandemic has unleashed.<sup>13</sup> A Washington Post/Ipsos poll that was released in May found that 20 percent of Hispanic adults and 16 percent of African-Americans reported being laid off or furloughed since the beginning of the outbreak, compared with 11 percent of whites and 12 percent of other races.<sup>14</sup> Meanwhile, as suggested above, people of color who have retained their jobs are disproportionately likely to continue to be exposed to the coronavirus as states attempt to expand economic activity.

- 10 Nania R. Blacks, Hispanics Hit Harder by the Coronavirus, Early U.S. Data Show. AARP [Internet]. 2020 May 1; Available from https://www.aarp.org/health/conditions-treatments/info-2020/minority-communities-covid-19.html
- 11 Centers for Disease Control and Prevention. COVID-19 in Racial and Ethnic Minority Groups. https://www.cdc.gov/coronavirus/2019-ncov/ need-extra-precautions/racial-ethnic-minorities.html
- 12 Williams V. Disproportionately Black Counties Account for Over Half of Coronavirus Cases in the U.S. and Nearly 60% of Deaths, Study Finds. Washington Post [Internet]. 2020 May 6. Available from: https://www.washingtonpost.com/nation/2020/05/06/study-finds-thatdisproportionately-black-counties-account-more-than-half-covid-19-cases-us-nearly-60-percent-deaths/?utm\_campaign=wp\_power\_ up&utm\_medium=email&utm\_source=newsletter&wpisrc=nl\_powerup&wpmm=1
- 13 Artiga S, Garfield R, Orgera K. Communities of Color at Higher Risk for Health and Economic Challenges due to COVID-19 [Internet]. 2020. Available from: https://www.kff.org/disparities-policy/issue-brief/communities-of-color-at-higher-risk-for-health-and-economicchallenges-due-to-covid-19/
- 14 Jan T, Clement S. Hispanics are Almost Twice as Likely as Whites to Have Lost Their Jobs Amid Pandemic, Poll Finds. Washington Post [Internet]. 2020 May 6. Available from: https://www.washingtonpost.com/business/2020/05/06/layoffs-race-poll-coronavirus/ ?utm\_campaign=wp\_power\_up&utm\_medium=email&utm\_source=newsletter&wpisrc=nl\_powerup&wpmm=1

The Centers for Disease Control and Prevention has issued recommendations for how health care systems and clinicians can help their patients address the challenges and larger disparities related to COVID-19. Two of particular relevance to the Forum are (1) identifying and addressing implicit bias that could hinder patient-provider interactions and communication and (2) promoting a trusting relationship by encouraging patients to call and ask questions.<sup>15</sup>

# **Linking Trust and Health Equity**

Of course, long before the coronavirus, we saw decades of evidence clearly demonstrating that health care experiences in America differ significantly based on race, socioeconomic status and other social factors. The National Academy of Medicine found in 2003 that across virtually every type of therapeutic intervention, members of minority groups receive poorer quality medical care than whites.<sup>16</sup> In the intervening years, even as we have expanded access to care and made progress on certain fronts, disparities in access to care and in health outcomes stubbornly persist. To cite just a few examples:

- African Americans are more likely than whites to die prematurely from stroke, heart disease or colorectal cancer.<sup>17</sup>
- Diabetes and heart disease are more prevalent among individuals with lower income levels and educational attainment.<sup>18</sup>
- Hispanics are three times as likely as whites and nearly twice as likely as African-Americans to be uninsured.<sup>19</sup>
- Maternal mortality is 193 percent higher for Blacks and 31 percent higher for Hispanics than whites.<sup>20</sup>

Inequities in access and outcomes have many causes, and there are many proposed approaches to addressing them. There is reason to believe that trust (or the lack thereof) plays a significant role in creating and/or worsening disparities, as, for example, individuals from groups that have historically been treated poorly by the system lose faith in it and decline to seek care from which they could benefit. At the same time, a focused effort to restore—and be worthy of—trust could potentially undo some of this past damage and help create the conditions for a more equitable system.

There is ample reason for individuals from underserved groups to view the U.S. health system skeptically, from the disparate outcomes of COVID-19 highlighted above to historical examples of outright prejudice. The "Tuskegee Study of Untreated Syphilis in the Negro Male" study offers the prototypical example of the latter, and illuminates the relationship between race, trust and health outcomes. For 40 years, from 1932 to 1972,

- 15 Centers for Disease Control and Prevention. COVID-19 in Racial and Ethnic Minority Groups. https://www.cdc.gov/coronavirus/2019-ncov/ need-extra-precautions/racial-ethnic-minorities.html
- 16 Smedley BD, Stith AY, Nelson AR. Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care. Washington, DC: National Academies Press; 2003. 1–764.
- 17 2017 National Healthcare Quality and Disparities Report [Internet]. Rockville; 2018. Available from: https://www.ahrq.gov/research/findings/ nhqrdr/nhqdr17/index.html
- 18 2017 National Healthcare Quality and Disparities Report [Internet]. Rockville; 2018. Available from: https://www.ahrq.gov/research/findings/ nhqrdr/nhqdr17/index.html
- 19 Chaudry A, Jackson A, Glied SA. Percentage of Uninsured Adults Ages 19 to 64, by Race and Ethnicity [Internet]. The Commonwealth Fund. 2019. Available from: https://www.commonwealthfund.org/chart/2019/percentage-uninsured-adults-ages-19-64-race-and-ethnicity
- 20 Williams DR, Cooper LA. Reducing racial inequities in health: Using what we already know to take action. Int J Environ Res Public Health. 2019;16(4).

the U.S. Public Health Service followed the cases of 600 lowincome African American men in Alabama, about 400 of whom suffered from syphilis. The men received sham treatments as government researchers pursued their stated goal of understanding the natural course of syphilis. Many died entirely preventable deaths.

The consequences of the Tuskegee study were deep and troubling, and reverberate to this day. African American men are less likely than white men to seek health care, and are more likely to die at earlier ages; indeed, the life expectancy for Black men at the age of 45 is more than three years lower than for non-Hispanic white men.<sup>21</sup> According to a recent study, one-third of this racial gap in life expectancy was attributable to the legacy of distrust the study created.<sup>22</sup>

Overall, African-American men have higher levels of medical mistrust than white men, and this mistrust is correlated with delays in care, lower health care utilization, and worse health outcomes.

Overall, African-American men have higher levels of medical mistrust than white men, and this mistrust is correlated with delays in care, lower health care utilization, and worse health outcomes.<sup>23</sup> One study found that Black men with prostate cancer reported a higher level of medical mistrust and lower quality of life (QOL) than white men, and that there was an association between mistrust and QOL.<sup>24</sup>

Of course, mistrust is not limited to African American men. There are numerous findings that patients of color have less trust in the health care system than white patients, and many researchers contend that these lower levels of trust help account for why patients of color are less likely than white patients to seek care, preventive services and surgical treatment.<sup>25</sup> As researchers worldwide rush to develop a COVID-19 vaccine, it is worth considering how eager patients of color will be to receive it. A Pew Research Center survey conducted this spring found that only 54 percent of Black adults said they would definitely or probably get a coronavirus vaccine if one were available today, compared to 74 percent of whites and of Hispanics.<sup>26</sup> These attitudes are consistent with pre-pandemic data about certain vaccines. In 2015, only 36 percent of non-Hispanic Black American adults received the flu shot, compared to 46.9 percent of non-Hispanic whites. Immunization rates were also lower for hepatitis, pneumonia and HPV vaccines. (Childhood immunization rates, however, were comparable between the groups.)<sup>27</sup>

A 2006 study found that nearly 45 percent of all African Americans reported low levels of trust in health care providers, compared to 33.5 percent of white Americans.<sup>28</sup> African Americans had lower levels of trust even after controlling for socio-demographics, prior health care experiences, and structural characteristics of care.

- 21 Frakt A. Race and Medicine: The Harm That Comes From Mistrust. New York Times [Internet]. 2020 Jan 13; Available from: https://www.nytimes.com/2020/01/13/upshot/race-and-medicine-the-harm-that-comes-from-mistrust.html
- 22 Alsan M, Wanamaker M. Tuskegee and the health of black men. Q J Econ. 2018;133(1):407–55.
- 23 Alsan M, Garrick O, Graziani G. Does diversity matter for health? Experimental evidence from Oakland. Am Econ Rev. 2019;109(12):4071–111.
- 24 Kinlock BL, Parker LJ, Bowie J V., Howard DL, LaVeist TA, Thorpe RJ. High levels of medical mistrust are associated with low quality of life among black and white men with prostate cancer. Cancer Control. 2017;24(1):72–7.
- 25 LaVeist TA, Nickerson KJ, Bowie JV. Attitudes about racism, medical mistrust, and satisfaction with care among African American and white cardiac patients. Med Care Res Rev. 2000;57 Suppl 1:146-61.
- 26 Gramlich J, Funk C. Black Americans Face Higher COVID-19 Risks, Are More Hesitant to Trust Medical Scientists, Get Vaccinated. Pew Research Center. 2020 June 4. Available from: https://www.pewresearch.org/fact-tank/2020/06/04/black-americans-face-higher-covid-19-risks-are-more-hesitant-to-trust-medical-scientists-get-vaccinated/
- 27 https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=22
- 28 Halbert CH, Armstrong K, Gandy OH, Shaker L. Racial differences in trust in health care providers. Arch Intern Med. 2006;166(8):896–901.

Among the African-American population, those whose medical care source was not a physician's office were the most likely to report low trust, suggesting that trust is harder to foster in care settings where continuity between patients and individual physicians is absent, such as hospital emergency departments or outpatient departments.

Another study found that African Americans were less likely than white patients to trust the technical judgment and interpersonal competence of physicians. The same was true for Hispanics, who exhibited deeper mistrust and were less likely than white patients to trust the fiduciary ethic or interpersonal competence of physicians.<sup>29,30</sup> In one study of Arkansas residents, Hispanic respondents were twice as likely to report lower levels of trust for doctors than non-Hispanic whites (28 percent vs 14 percent), and 34 percent reported lower trust in medical professionals of a different racial/ethnic background.<sup>31</sup>

Another study, which looked at Hispanic young adults living in Oregon, found that although 73 percent said they were either moderately or very satisfied with the health care services they had used during the previous year, medical mistrust and perceived discrimination were the most common causes of dissatisfaction.<sup>32</sup> (It is worth noting that the heterogeneity of the Hispanic community means that trust may vary widely between, say, those of Mexican descent and those of Cuban or Puerto Rican descent.)

Even leaving aside race and ethnicity, low-income patients generally exhibit less trust in their physicians. Only 47 percent of Americans with incomes below \$30,000 said that doctors can be trusted, compared to 63 percent of Americans with incomes above that level.<sup>33</sup> Indeed, when researchers interviewed patients for a 2016 study, they found that "the issue lower-income participants were most passionate about" was their "widespread distrust of the health care system and the feeling that they were seen as 'less than' by health care professionals."<sup>34</sup> These patients were mostly critical of physicians, rather than nurses or other providers. They offered numerous examples of what they perceived as a lack of trust and respect, including "providers avoiding eye contact, speaking condescendingly, showing physical disgust when touching patients, brushing off patient concerns and symptoms, and ignoring adverse events that patients reported from prescribed treatments."

How does this mistrust relate to the unequal outcomes that NAM and many others have reported? The studies connecting reduced life expectancy to the Tuskegee experiment and reduced quality of life for distrustful prostate cancer patients are two examples of research that directly links mistrust to poor outcomes. Researchers have also found an association between medical mistrust and increased anxiety and depression among African American women with breast cancer.<sup>35</sup> Multiple studies have found a link between trust and utilization of preventive services among African-American populations, which could reasonably be expected to have downstream consequences on health outcomes.<sup>36,37</sup> Relatedly, researchers found that Hispanics were nearly twice as likely as whites to

- 29 Sewell AA. Disaggregating ethnoracial disparities in physician trust. Soc Sci Res. 2015 Nov;54:1–20.
- 30 Armstrong K, Ravenell KL, McMurphy S, Putt M. Racial/Ethnic Differences in Physician Distrust in the United States. Amer Journ of Public Health 2007; 97(7): 1283-89.
- 31 Boyas J, Valera P. Determinants of Trust in Medical Personnel. Hisp Heal Care Int. 2011;9(3):144–52.
- 32 Lopez-Cevallos DF, Harvey SM, Warren JT. Medical Mistrust, Perceived Discrimination, and Satisfaction With Health Care Among Young-Adult Rural Latinos. Journ Rural Health 2014; 30(4):344-351.
- 33 Blendon RJ, Benson JM, Hero JO. Public trust in physicians U.S. medicine in international perspective. N Engl J Med. 2014;371(17):1570–2.
- 34 Duke CC, Stanik C. Overcoming lower-income patients' concerns about trust and respect from providers [Internet]. Bethesda (MD): Health Affairs; 2016 Aug 11. Available from: https://www.healthaffairs.org/do/10.1377/hblog20160811.056138/full/
- 35 Sheppard VB, Harper FWK, Davis K, Hirpa F, Makambi K. The importance of contextual factors and age in association with anxiety and depression in black breast cancer patients. Psychooncology. 2014;23(2):143-150. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/ PMC4144019/pdf/nihms558796.pdf
- 36 O'Malley AS, Sheppard VB, Schwartz M, Mandelblatt J. The role of trust in the use of preventive services among low-income African-American women. Prev Med. 2004;38(6):777-785.
- 37 LaVeist TA, Isaac LA, Williams KP. Mistrust of health care organizations is associated with underutilization of health services. Health Serv Res. 2009;44(6):2093–105.

report that fear of being a "guinea pig" and lacking trust in clinicians would make them unwilling to participate in cancer screenings. This is particularly significant since there is evidence that disparities in cervical cancer incidence and mortality rates for Hispanics from the disease are partly attributable to lower screening rates.<sup>38</sup>

## **Contributors to Inequity**

There are a number of factors that contribute to and/or reveal inequities in the health care system. During the Forum, we will discuss how thinking about these factors may be changed or deepened by the COVID-19 experience. We will also consider new relevant research questions that the epidemic has brought to the surface.

Some of these contributing factors are structural, such as the nature of the health care workforce. Others seem to arise from our subconscious and threaten to undermine efforts to create a fairer system, like the implicit biases that can shape our worldview without our awareness and that may be all the more powerful during times of stress and upheaval. This section of the paper offers brief descriptions of some of these factors and possible ways to address the challenges they present.

## **Unconscious Bias**

**The problem:** Bias against individuals from underserved populations can be overt or implicit, and can even be inadvertently incorporated into the way a new technology is designed to work. Being subjected to bias inevitably makes individuals reluctant to trust in the health care system, with all the consequences that entails.

In the time of a health care crisis, a lack of trust among patients could have a particularly stark set of impacts, such as people suffering from COVID-19 who might decline or delay seeking care. Meanwhile, some worry that bias among health care professionals itself will go unchecked under the extraordinary stress of the pandemic. "We know that those biases tend to be increased at a time when there's a lot of stress on people," said Lisa Cooper, MD, MPH, a Bloomberg Distinguished Professor, Equity in Health and Healthcare and Professor of Medicine at Johns Hopkins University.

There are early signs that African American patients have been less likely to be tested for COVD-19, with one early study (which has not gone through peer review) showing that Black patients were six times less likely to get treatment or testing than white patients. The National Medical Association, the nation's largest organization representing Black physicians, has called for a federal study of the role bias may have played in the testing and treatment of African American patients. The CDC has said that it cannot quantify the role of implicit bias, but in a statement it said: "Becoming aware of and reflecting on one's biases to help ensure they do not impact decisions is a potentially lifesaving step for clinicians to undertake."<sup>39</sup>

Implicit bias exists outside of conscious awareness, and is frequently at odds with one's personal beliefs, making it difficult to control or even acknowledge. The first study to show unconscious bias among physicians involved internal medicine and emergency medicine residents in Atlanta and Boston in 2005.<sup>40</sup> The physicians took a survey to measure any explicit bias they had in favor of or against Black or White patients, as well as any implicit bias, as measured through the Implicit Association Test (IAT). Although the residents demonstrated no explicit

<sup>38</sup> Davis JL, Bynum SA, Katz R V, Buchanan K, Green BL. Sociodemographic differences in fears and mistrust contributing to unwillingness to participate in cancer screenings. J Health Care Poor Underserved. 2012;23(4 SUPPL.):67–76.

<sup>39</sup> Eligon J, Burch A. Questions of Bias in Covid-19 Treatment Add to the Mourning for Black Families. New York Times [Internet]. 2020 May 10; Available from: https://www.nytimes.com/2020/05/10/us/coronavirus-african-americans-bias.html?utm\_campaign=wp\_the\_daily\_ 202&utm\_medium=email&utm\_source=newsletter&wpisrc=nl\_daily202

<sup>40</sup> Green AR, Carney DR, Pallin DJ, Ngo LH, Raymond KL, lezzoni LI, et al. Implicit bias among physicians and its prediction of thrombolysis decisions for black and white patients. J Gen Intern Med. 2007;22(9):1231–8.

bias, the IAT revealed that they had an implicit preference in favor of white Americans and held stereotypes of Black Americans as being less cooperative, both with medical procedures and generally.

The researchers then compared the residents' levels of implicit bias with their decisions whether to order thrombolysis when presented with clinical vignettes featuring either a white or Black patient. They found a direct relationship between physicians' implicit bias in favor of white patients and their likelihood of recommending thrombolysis for white patients but not Black patients who would benefit from it. Interestingly, the authors noted that physicians who understood that the study was designed to explore bias, and who in fact had higher levels of implicit bias in favor of whites, were actually more likely to recommend thrombolysis to Black patients than their peers who had low levels of bias. They interpreted this finding to suggest that people who understand their own potential biases can modify their behavior in positive ways.

The thrombolysis study was not an outlier. A systematic review found that 14 of 15 relevant studies discovered low to moderate levels of implicit racial/ethnic bias among health care professionals; the levels of bias were similar to that of the general public. Implicit bias significantly influenced patient-provider interactions, treatment decisions, treatment adherence and patient health outcomes.<sup>41</sup> For example, one study showed correlation between physicians' implicit bias in favor of whites on the IAT and African-American patients' perceptions of poorer communication and lower quality care.<sup>42</sup> Another study showed that pediatricians with a high degree of implicit bias toward whites were less likely to prescribe narcotic pain medication for African American patients than white patients, even where the standard of care supported the prescription.<sup>43</sup> There is also evidence that implicit bias leads women to be less likely to receive clinically appropriate knee arthroplasty or be diagnosed with chronic obstructive pulmonary disease (COPD).<sup>44</sup>

The exponential growth of technology, and its reliance on algorithms to guide care decisions, has opened a new window for unconscious bias. A recent study showed bias in favor of whites and against African-Americans in a program that health systems used to identify which patients to include in a program for those with complex health needs.<sup>45</sup> The bias arose because programmers trained the algorithm to use the amount of money spent on patients' care as a proxy for the complexity of their health needs. Because white patients on average have greater access to and ability to afford more care, this had the effect of prioritizing white patients for the program; indeed, the authors estimate that remedying the disparity would increase the percentage of African-Americans in the program from 17.7 to 46.5 percent.

The exponential growth of technology, and its reliance on algorithms to guide care decisions, has opened a new window for unconscious bias.

- 41 Hall WJ, Chapman MV, Lee KM, Merino YM, Thomas TW, Payne BK, et al. Implicit racial/ethnic bias among health care professionals and its influence on health care outcomes: A systematic review. Am J Public Health. 2015;105(12):e60–76. https://ajph.aphapublications.org/ doi/abs/10.2105/AJPH.2015.302903
- 42 Cooper LA, Roter DL, Carson KA, Beach MC, Sabin JA, Greenwald AG, et al. The associations of clinicians' implicit attitudes about race with medical visit communication and patient ratings of interpersonal care. Am J Public Health. 2012;102(5):979–87.
- 43 Sabin JA, Greenwald AG. The influence of implicit bias on treatment recommendations for 4 common pediatric conditions: Pain, urinary tract infection, attention deficit hyperactivity disorder, and asthma. Am J Public Health. 2012;102(5):988–95.
- 44 Chapman EN, Kaatz A, Carnes M. Physicians and implicit bias: How doctors may unwittingly perpetuate health care disparities. J Gen Intern Med. 2013;28(11):1504–10.
- 45 Obermeyer Z, Powers B, Vogeli C, Mullainathan S. Dissecting racial bias in an algorithm used to manage the health of populations. Science (80-). 2019;366(6464):447–53.

**What can be done:** The 2003 NAM study called for a "sustained long-term effort" to combat implicit bias, noting that many physicians find it difficult to recognize such bias in themselves. NAM favorably cited a number of approaches to addressing the problem, including tracking patterns of care by race and ethnicity, teaching and discussing stereotyping and bias at every level of undergraduate and graduate medical education and including faculty physicians in that effort, and discontinuing the practice of automatically labeling patients by race in the initial description of them in the examination room.<sup>46</sup> Observers have suggested that all nursing and allied health schools, hospitals and delivery systems should provide bias training for all personnel who interact with patients, including skills and tactics health professionals can use to address their own bias.

One specific strategy that appears to succeed in reducing implicit bias is individuating: making a conscious effort to focus on specific information about an individual, so that information is more consequential than the individual's social category.<sup>47</sup> In one study, initial gender differences in diagnosing COPD disappeared when physicians were presented with spirometry data that indicated the presence of the disease.<sup>48</sup>

Another strategy is perspective-taking, a conscious attempt to envision another person's viewpoint. In one study, researchers showed nurses pictures of white or African-American patients with genuine expressions of pain and asked them to make recommendations for pain medication. Nurses who were simply told to use their best judgment recommended significantly more pain medication for white patients, but nurses who were instructed to imagine how the patient felt recommended equal analgesic treatment regardless of race.<sup>49</sup>

Other suggestions to combat implicit bias include developing measures to assess it, devoting more resources to interpreters and translation services, establishing chief equity officer positions in delivery systems, and diversifying the health care workforce,<sup>50</sup> which will be discussed in the next section.

In the case of the algorithm, the article's authors actually collaborated with the software developer to develop an index variable that combined health prediction with cost prediction; this change reduced bias by 84 percent. This sort of close attention to the data that programmers use to feed the algorithm offers an opportunity to enable the next generation of technology to help overcome the biases that have marked our health care system, rather than replicating them.

#### The Health Care Workforce

**The problem:** Of the physicians who were practicing medicine in 2018, only 5.8 percent were Hispanic and 5 percent were African-American.<sup>51</sup> The numbers of medical school graduates in 2019 were little different: 5.3 percent were Hispanic and 6.2 percent African-American. (An additional 8 percent of graduates identified themselves as of multiple races/ethnicities.) These numbers lag those groups' share of the population by a significant margin, as Hispanics constitute more than 17 percent of the U.S. population and African-Americans account for 13 percent. Meanwhile, 35.8 percent of practicing physicians and 47.9 percent of 2019 medical school graduates were women.

- 46 Smedley BD, Stith AY, Nelson AR. Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care. Washington, DC: National Academies Press; 2003. 1–764.
- 47 Chapman EN, Kaatz A, Carnes M. Physicians and implicit bias: How doctors may unwittingly perpetuate health care disparities. J Gen Intern Med. 2013;28(11):1504–10.
- 48 Chapman KR, Tashkin DP, Pye DJ. Gender bias in the diagnosis of COPD. Chest. 2001;119(6):1691–5.
- 49 Drwecki BB, Moore CF, Ward SE, Prkachin KM. Reducing racial disparities in pain treatment: the role of empathy and perspective-taking. Pain. 2011;152(5):1001–6.
- 50 Agrawal S, Enekwechi A. It's Time to Address the Role of Implicit Bias Within Health Care Delivery [Internet]. Health Affairs Blog. 2020. Available from: https://www.healthaffairs.org/do/10.1377/hblog20200108.34515/full/
- 51 Diversity in Medicine: Facts and Figures 2019 [Internet]. AAMC. 2019. Available from: https://www.aamc.org/data-reports/workforce/ interactive-data/figure-18-percentage-all-active-physicians-race/ethnicity-2018

Creating a fair playing field for all who seek a career in the health professions is an important value in its own right. There is also evidence that a diverse workforce can make a meaningful difference in health outcomes by building trust. For example, a recent study found that Black men who were treated by Black physicians agreed to receive more highly recommended preventive services (e.g., flu shots) than Black men who received care from non-Black doctors. The authors attributed the difference to better communication and more trust.<sup>52</sup> The consequences were significant; the authors found that if all Black men received the same increase in preventive services, along with appropriate follow-up care, differences in the mortality rate for cardiovascular disease would decline by 19 percent and the total Black-white life expectancy gap would shrink by 8 percent.

**What can be done:** Experts have long called for focused attention on diversifying the pool of medical students. In response, medical school leaders have adopted formal standards aimed at achieving institutional diversity and investing in pipeline programs designed to increase the number of qualified applicants from diverse backgrounds. In addition, almost all medical schools have adopted holistic admissions approaches that seek to evaluate applicants as individuals rather than relying only on test scores and grades.<sup>53</sup>

Despite these efforts, progress thus far has been modest at best; the effort to increase the number of African American males in medical school has been particularly unsuccessful. Additional suggestions for meeting this and other diversity goals include:

- Active involvement by medical school leadership in the admissions process, including offering incentives for leaders to prioritize diversity and inclusion;
- Reviewing and updating admissions policies and practices and emphasizing success of students admitted through holistic review<sup>54</sup>;
- Continued support and development of premedical programs, with creative thinking about how to engage Black men and others from underrepresented communities, who are more likely to experience a decline in their interest in pursuing medicine while they are in college<sup>55</sup>; and
- Engaging more with the broader community, such as developing relationships with community colleges and high schools to identify and encourage students who might pursue medical careers.<sup>56</sup>

Of course, increasing the diversity of the health care workforce is necessary but not sufficient to improve the trust of people from underserved populations. As discussed in the previous section, members of the health care workforce across the board need to better understand and address their own biases, and the structural biases inherent in the larger health care system, in order to gain and maintain trust.

- 54 Association of American Medical Colleges. Altering the course: Black males in medicine. Assoc Am Med Coll [Internet]. 2015;1–49. Available from: https://members.aamc.org/eweb/upload/Altering the Course - Black Males in Medicine AAMC.pdf
- 55 Morgan HK, Haggins A, Lypson ML, Ross P. The Importance of the Premedical Experience in Diversifying the Health Care Workforce. Acad Med. 2016;91(11):1488–91.
- 56 Agrawal S, Enekwechi A. It's Time to Address the Role of Implicit Bias Within Health Care Delivery [Internet]. Health Affairs Blog. 2020. Available from: https://www.healthaffairs.org/do/10.1377/hblog20200108.34515/full/

<sup>52</sup> Alsan M, Garrick O, Graziani G. Does diversity matter for health? Experimental evidence from Oakland. Am Econ Rev. 2019;109(12):4071–111.

<sup>53</sup> Diversity in Medicine: Facts and Figures 2019 [Internet]. AAMC. 2019. Available from: https://www.aamc.org/data-reports/workforce/ interactive-data/fostering-diversity-and-inclusion

## **Research Disparities**

**The problem:** The research community has received substantial criticism for a lack of diversity among the population participating in clinical trials. Racial and ethnic diversity leads to more generalizable research findings, more equal access to the direct benefits of participation, and accuracy of subgroup analyses.<sup>57</sup> Despite its importance and a series of efforts from federal agencies that sponsor research to address diversity, research participation by members of minority groups continues to lag well behind their share of population. For example, in 1997, 92 percent of participants in clinical trials for treatments targeting cancer, central nervous system diseases, and heart disease were white. In 2014, that number had fallen somewhat but still stood at 86 percent.<sup>58</sup>

Concern about access to clinical trials extends to therapies to treat or prevent COVID-19. Reginald Swift, the CEO of biotechnology company Rubix Life Sciences, told the Guardian (UK) newspaper that he expects to see racial disparities in trials for experimental drugs. He said some trials have only allowed patients without underlying conditions, negatively affecting African-Americans. In addition, patients with low-cost insurance plans may be denied coverage for trials, penalizing low-income Americans.

Mistrust among patients from low-resource communities remains a significant stumbling block to assuring that they have equal opportunity to participate in and benefit from medical research. Indeed, a series of literature reviews has confirmed that participant trust is one of the most significant factors limiting research participation.<sup>59</sup>

Although somewhat dated, findings from focus groups in Atlanta from the 1990s shed light on the attitudes of African Americans toward participating in medical research. Participants offered a number of reasons why they would be reluctant to join trials. Some were unrelated to trust, such as inconvenience or a fear of injections. But they also shared their doubts about physicians' honesty with them about risks, and expressed concern that anything good that came out of the research would not benefit African Americans because of racial discrimination and poverty.<sup>60</sup> Mistrust among patients from low-resource communities remains a significant stumbling block to assuring that they have equal opportunity to participate in and benefit from medical research.

The group members' distrust ran deep. A number of participants expressed fear of being treated as "guinea pigs" and of being infected with an "unknown virus" similar to HIV. A lack of trust even caused some participants to view the informed consent process as an attempt only to insulate those running clinical trials from legal liability. Here, too, the Tuskegee study provided a poisonous context, with focus group participants referencing it repeatedly, even before the moderator raised it.

<sup>57</sup> George S, Duran N, Norris K. A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. Am J Public Health. 2014;104(2):16–31.

<sup>58</sup> Knepper TC, McLeod HL. When will clinical trials finally reflect diversity? Nature. 2018;557(7704):157-159.

<sup>59</sup> George S, Duran N, Norris K. A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. Am J Public Health. 2014;104(2):16–31.

<sup>60</sup> Corbie-Smith G, Thomas SB, Williams MV, Moody-Ayers S. Attitudes of African Americans toward participation in medical research. J Gen Intern Med. 1999;14(9):537–46.

A more recent survey conducted in New York found that Hispanics were also more likely to perceive discrimination in research, and that participants who were interviewed in Spanish had stronger perceptions of discrimination than English-language respondents.<sup>61</sup> Researchers have also found that people with disabilities have pervasive research trust issues.<sup>62</sup>

What can be done: Despite their skepticism, participants in the Atlanta focus groups suggested that participation could be improved by more honest and respectful communication from physicians and other research personnel and by providing complete information about risks and benefits. Participants stressed giving participants ample time to consider their participation, providing information in multiple forms about the research (e.g., written, video, etc.), and offering them the opportunity to speak with the physicians involved in the study. One stated: "[I want an] explanation by a person who is comfortable to talk to and who is comfortable talking with me. You have to have a level of trust."

Those who have studied the issue have suggested that researchers develop tailored approaches to address the concerns of people from different backgrounds, such as linguistically and culturally appropriate educational interventions that explain the risks and benefits of research for people with limited English. They also advise seeking to build relationships with a community before seeking research participants from it.

Other suggestions include treating informed consent as an ongoing process rather than a point-in-time decision, supporting patients in making informed decisions throughout a clinical trial. Others have suggested focusing on retention of participants, such as by partnering with community organizations, employing investigators and staff from the same minority communities as participants, and retaining interviewers over time to improve continuity.<sup>63</sup>

## **Patient Safety/Diagnostic Errors**

**The problem:** As discussed above, the health outcomes and experiences of women and people from underserved communities are often inferior to the outcomes and experiences of white men. The evidence is mixed about whether patient safety is worse overall for women and the underserved.<sup>64</sup> However, there are specific areas of care in which women and African American patients are more likely to experience patient safety events and diagnostic errors and shortcomings.<sup>65</sup>

For example, women have a lower likelihood of receiving proper and timely diagnoses of cancer and coronary heart disease compared to men, while Black patients are less likely to be correctly diagnosed with depression. Women with heart disease have higher mortality rates than men from heart attacks,<sup>66</sup> and were also 25 percent more likely to report poor patient-provider communication and 12 percent more likely to experience lower health satisfaction than men.<sup>67</sup> We also know that patients with limited English proficiency experience high rates of medical errors and worse clinical outcomes than English-speaking patients.<sup>68</sup>

- 61 Smirnoff M, Wilets I, Ragin DF, Adams R, Holohan J, Rhodes R, et al. A paradigm for understanding trust and mistrust in medical research: The Community VOICES study. AJOB Empir Bioeth. 2018;9(1):39–47.
- 62 McDonald KE, Kidney CA, Patka M. 'You need to let your voice be heard': research participants' views on research. J Intellect Disabil Res. 2012;57(3):216–25.
- 63 George S, Duran N, Norris K. A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. Am J Public Health. 2014;104(2):16–31.
- 64 Okoroh JS, Uribe EF, Weingart S. Racial and ethnic disparities in patient safety. J Patient Saf. 2017;13(3):153–61.
- 65 Piccardi C, Detollenaere J, Vanden Bussche P, Willems S. Social disparities in patient safety in primary care: a systematic review. Int J Equity Health. 2018;17(114):1–9.
- 66 Bugiardini R, Ricci B, Cenko E, Vasiljevic Z, Kedev S, Davidovic G, et al. Delayed care and mortality among women and men with myocardial infarction. J Am Heart Assoc. 2017;6(8).
- 67 Okunrintemi V, Valero-Elizondo J, Patrick B, Salami J, Tibuakuu M, Ahmad S, et al. Gender Differences in Patient-Reported Outcomes Among Adults With Atherosclerotic Cardiovascular Disease. J Am Heart Assoc. 2018;7(24):1–11.
- 68 Green AR, Nze C. Language-Based Inequity in Health Care: Who Is the "Poor Historian"? AMA J Ethics. 2017;19(3):263-71.

What can be done: One important step would be to improve data collection and promote research to better understand links between patient safety, gender and minority group status. A 2017 literature review found that it was difficult to disentangle whether patient safety issues were driven more by the characteristics of hospitals where minority patients tend to seek care (but are as likely to affect white men seeking care at those institutions as anyone else) or whether they were in fact more likely to affect underserved populations.<sup>69</sup> (Obviously, attention must be paid to providing more equitable care in either event.) The authors wrote that "there is a paucity of research in patient safety that includes race/ethnicity and how its interaction with other demographic factors such as education, income and occupation impacts quality of care."

A recent article in the New England Journal of Medicine explores how the techniques of the patient safety movement—itself essential to building trust—could be applied to enhance equity. The authors argue that both safety and equity are "fundamental dimensions of health care quality," and that among other things, both involve cognitive, often subconscious, biases.<sup>70</sup> They note that over the last two decades, health care organizations have created strong safety systems with technology and infrastructure resources that can be leveraged to achieve equity goals. For example, they recommend that systems stratify safety data by race, sex, and other important variables to identify inequities and potential solutions; for example, improving translation services if the data shows that negative outcomes are occurring more frequently in non-English speaking patients. More generally, the infrastructure that systems have built to improve safety—processes, prompts, case review meetings, etc.—can be applied to equity-focused initiatives.

There have been a number of suggestions specific to improving cardiac care for women. This includes the creation of women's cardiovascular health programs in health systems, which could identify at-risk women, improve diagnosis, advance research, and raise awareness among clinicians and the community about differences in how women and men experience heart disease. Other proposals have been to improve the formal curriculum in medical schools related to cardiovascular disease (CVD) and require rotations for residents and fellows in women's CVD programs.<sup>71</sup> Some of these lessons learned may be useful in addressing disparities stemming from race, ethnicity and economic status.

#### Conclusion

The U.S. health system faced significant challenges of trust and of equity before the COVID-19 outbreak; the gravity of those challenges and the moral imperative to respond to them have heightened dramatically. Over the course of the Forum, participants will explore some of the factors that have created mistrust and how we can address them, including ideas for the kind of research, large scale innovations efforts and policy changes that could help create a more just system. We hope this background paper provides useful context for your participation in the meeting.

- 69 Okoroh JS, Uribe EF, Weingart S. Racial and ethnic disparities in patient safety. J Patient Saf. 2017;13(3):153-61.
- 70 Sivashanker K, Gandhi TK. Advancing Safety and Equity Together. N Engl J Med. 2020;382(4):301–3.
- 71 Gulati M. Improving the Cardiovascular Health of Women in the Nation: Moving beyond the Bikini Boundaries. Circulation. 2017;135(6):495–8.

