

Beacon of Hope: Addressing health disparities through holistic community-based collective action ^[1]

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Black/African Americans have endured education and health disparities in the United States (US) for four centuries. Access to basic education was illegal for Black/African Americans in America, and health care where it existed was often denied. Dating back to the severe inequalities imposed by slavery, evidence suggests that the public health system in the US subsequently developed in ways that have sustained racially divided health care.¹

Well-documented examples of disenfranchisement of Black/African Americans in health and science include the Tuskegee Syphilis Study, in which patients were denied standard antibiotic treatment in order to investigate the progression of untreated syphilitic disease, and the story of Henrietta Lacks, whose cervical cancer cells were surreptitiously commercialized for research purposes without her knowledge.^{2,3} Tragically, however, most accounts of health disparities affecting Black/African Americans throughout history are likely to have been obscured from view.

Likewise, access to equal education was denied to Black/African Americans, even after the end of slavery. Schools were segregated, and those in Black/African American communities had significantly fewer resources. A few teachers' colleges for *free Blacks* were founded prior to the Civil War, and after emancipation additional colleges were founded to educate former slaves. These schools, today's Historically Black Colleges and Universities (HBCUs), were the only post-secondary institutions that Black/African Americans could attend until May 17, 1954.

In the current era, there are strong indications that health disparities affecting minority groups are endemic in the US. Compared with non-Hispanic whites, Black/African Americans have a lower life expectancy, a higher mortality rate from cancer, a dramatically greater likelihood of diseases such as asthma, and significantly increased rates of infant mortality.⁴ Some of these health disparities are further exacerbated by minorities' increased exposure to negative environmental factors such as air pollution, excessive heat, and poorer water quality.⁵ The COVID-19 pandemic further demonstrated long-standing, systemic racial inequities in health as measured by disproportionate rates of hospitalization and death in minority groups.⁶

The COVID-19 pandemic has also revealed a reluctance among minority patients to participate in clinical trials and associated vaccine hesitancy. The exclusion from the research and development ecosystem, which existed and extends beyond the pandemic, is both the result of, and results in mistrust and a delayed uptake of life-saving innovative medicines and effective care models, further exacerbating racial disparities in care and outcomes.

The lack of diversity not only exists among trial participants, but also among clinical trial

investigators, medical school students, and physicians. In 2019, Black/African Americans comprised 13.4% of the US population, but only 6.2% of medical school graduates, and 5% of practicing physicians with an even smaller proportion identified as clinical trial investigators.⁷ A sustained effort engaging Historically Black Medical Schools (HBMSs) and HBCUs is needed to increase diversity among care providers, clinical researchers, and patients participating in clinical studies to both build mutual trust and improve health outcomes across communities in the US.

Looking ahead, we envision a country that embraces equity in health for all. We believe that the next generation of researchers in health, science, and technology will have a particularly essential role to play. Furthermore, we believe there is urgency to empower these future leaders with the education and technology needed to bring full visibility to the breadth and nature of health disparities in the US and to design and implement enduring solutions.

To achieve a paradigm shift in education and health equity, it will take the concerted action of diverse stakeholders across public and private sectors. Inspired by the opportunity to bring to bear synergistic expertise and resources across disciplines, Novartis is convening this initial group of stakeholders to collaborate with the aim of generating robust data to find solutions that address systemic disparities in education and health outcomes to create greater diversity, equity and inclusion across the research and development ecosystem.

A guiding principle to our approach is to co-create programs under the direction of Black/African American community members and other minority groups. We also recognize that achieving sustained changes in health equity at population scale is a long-term endeavor that will take a sustained and multifaceted effort to realize.

Over an initial period of ten years, this holistic commitment will focus across four key areas:

- 1. Enable the next generation of Black/African American leaders.** We will work to create equitable access to affordable high-quality digital learning and education for professional development of future leaders, particularly in health and social equity-related fields. For example, as an initial step, the Novartis US Foundation is working with partners such as the Thurgood Marshall College Fund (TMCF) to establish faculty research grants and support annual scholarships over 10 years to HBCU students. This will also include career readiness and leadership development for students through mentorship and internships to help ensure the students are prepared to succeed in economically sustainable careers after graduation. The faculty research grants will focus on health equity and provide data for actionable solutions. Our aim is to ultimately help HBCU college and graduate level students achieve their ambitions to excel academically and professionally, while contributing to the reduction of the generational wealth gaps that impact Black/African American families.
- 2. Support the establishment of Digitally Enabled Clinical Trial Centers of Excellence** managed and led by clinical researchers of color to increase diversity in clinical trials. Ultimately, this will contribute toward developing self-sustaining clinical trial centers, increasing trust and diversity among principal investigators and trial managers, and improving the quality and inclusivity of clinical trials, while contributing to improved health outcomes for communities of color.
- 3. Support research and validation of existing data standards** that drive diagnosis, clinical trial endpoints and population health policy. The COVID-19 pandemic, for

example, highlighted the potential limitations of pulse oximeters in overestimating blood oxygen levels in people with darker skin color, which could result in biased treatment decisions and poorer patient outcomes. Technology has revolutionized many aspects of healthcare for the better, but there is increasing evidence that some medical devices, as well as search algorithms used in telemedicine, may inadvertently contribute to discrimination in the US health care system in circumstances where the underlying software was not developed using adequately representative data across ethnic and racial groups.^{8,9}

- 4. Establish Digitally-Enabled Research Centers on the impact of the environment and climate change on health**, with an emphasis on preventing the exacerbation of health disparities. Climate change is predicted to have profound implications on human health. There is increasing evidence that a lack of urban green space, heat events, pollution, flooding, and natural disasters disproportionately affect communities of color.^{10,11} We will work to advance research focused on the impact of environment and climate change on human health to help reduce the burden on already marginalized communities.

This is the beginning of our work together to address health disparities in the US. While this partnership involves Historically Black Colleges and Universities at the start, we acknowledge the health disparities affecting other minority populations and will work to expand the scope of these efforts as soon as possible to other racial and ethnic groups.

We believe that through concerted action we can deliver measurable impact. Moreover, we hope that through our efforts we can help to enlist others to this cause, including other biotechnology and pharmaceutical companies who share the same vision and objectives. Upon signature of this pledge, as a first step toward our planned 10-year collaboration, our goal is to spend the next 6 months co-creating potential solutions with the communities we aim most to impact, for we are united in our mission to positively bend the curve of life for all.

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