

# Confronting Healthcare Equity: NADPH's Crusade To Eliminate US Healthcare Disparities

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Dr. Alex Carlisle NADPH

Artificial Intelligence (AI) is propelling the next economic revolution but readying the entire workforce for this change will be an uphill battle. While the United States continues to lead globally in AI innovation, there is also a failure to adequately foster the development and equitable inclusion of talent in STEM from historically underrepresented communities. This has crippling effects not only from an economic perspective, but has downstream implications in all areas of industry, education, and more acutely in healthcare where equal access has been elusive.

There have been legislative and executive measures like Obama's [National Science and Technology Council Committee on Technology report Preparing for the Future of Artificial Intelligence](#), and [National Bioeconomy Blueprint](#), as well as Biden's [EO 14081](#) to address these barriers. A core focus is boosting STEM training in underrepresented communities to build a diverse talent pool for the growing AI workforce.

At the center of this mission, is Dr. Alex Carlisle, PhD, CEO of [The National Alliance against Disparities in Patient Health](#) (NADPH), who has been dedicated to addressing disparities in access to precision-based healthcare in under-resourced and marginalized communities. As technologies progress, they are also committed to involving and reskilling these same communities to ensure no one is left behind.

Dr. Carlisle's journey began in Harlem, where, while completing his post-graduate degree, he actively volunteered in community programs spearheaded by his grandfather, the late Mr. Roscoe Bradley, whose organization, the Colonial Park Community Association, led the development of community initiatives to combat prevalent issues of the time. Carlisle reflects on the aftermath of the post-Vietnam War and the wave of challenges, with war veterans returning home with addictions to heroin, exacerbating the issues of rampant unemployment and crime in New York. Over time they were confronted by the rise of the crack epidemic. It was his grandfather and this familial legacy—a deep-rooted sense of community service that guided his career journey.

For Dr. Carlisle, this was the most challenging but also the most rewarding:

"The power to improve the human condition through direct interaction is something that is often overlooked given the increasing virtualization of today's society. Working with my grandfather's organization, Colonial Park, early in my career, and seeing how my efforts could directly help someone improve their life, was a deeply moving and gratifying experience and I knew that I wanted to affect that type of impact on people's lives through my love of science and chosen career path."

After completing his postdoctoral training in molecular oncology at the National Cancer Institute (NCI), Dr. Carlisle chose to work in oncology research, with a desire to move the needle in finding a cure for cancer. As his career progressed, he found himself working on ground-breaking projects in prestigious institutions such as Fox Chase Cancer Center, Children's Hospital of Philadelphia, Inova Health Systems, and Northrop Grumman Health. Despite the significant strides made in cancer research, he began feeling a disconnect between the work he was doing and its direct impact on people's lives.

"My experiences in community service taught me the value of making a tangible impact, such as helping individuals overcome addiction and find employment. This realization reshaped my commitment to community welfare. However, the turning point came when I felt that the impact of my work in oncology research was becoming increasingly focused, specialized, and remote from the broader community, and I yearned for a more direct, meaningful contribution to society."

## **NADPH Takes Shape**

In 2008, Dr. Carlisle continued to think about the access gaps in health and economics that persisted in New York, years after his volunteer work with his grandfather. During this time, the mortgage crisis delivered a severe economic blow around the world, triggering panic, bankruptcy and massive unemployment in its wake. This was also a time when the convergence of scientific and technological innovations, application of these innovations to personalize and improve healthcare, was being demonstrated to have a significant impact on job growth and economic development across various states through investments in translational and precision-medicine based research institutes. It was at this time that Dr. Carlisle initiated a project to bridge this widening gap and bring advanced medical technology to underserved communities. This project laid the foundation for what eventually became NADPH, officially established in 2017. The primary objective was to democratize healthcare by introducing personalized medicine and cutting-edge technology to communities facing disparities in medical services.

NADPH's belief? Everyone deserves access to high-quality healthcare, regardless of their background or socioeconomic status. It was only the beginning, Dr. Carlisle recalls,

"In 2017, the inception of NADPH (National Alliance for Disparities in Patient Health) marked a significant shift in my mission to democratize advanced healthcare technologies. Originally, my vision was to work with the late N.Y. State Senator William Perkins to establish the Harlem Personalized Medicine Institute, a cutting-edge research facility to be developed in partnership with Gerry McDougall and PriceWaterhouseCoopers (PwC) that aimed at fostering innovation, technology development, and intellectual property creation."

The project faced obstacles and Dr. Carlisle admitted the goals were ambitious as they were unable to secure the necessary investments. They decided to pivot, acknowledging the need for a more community-centric strategy. Instead of developing a facility that served as the panacea, Dr. Carlisle's team recognized that the NADPH needed to focus on empowering underserved communities through data literacy and ownership of their information:

"We recognized that access to technology and knowledge is pivotal for the future of healthcare, especially in areas that are often left behind in technological advancements. Our commitment is to bridge this gap and empower individuals to understand, control, and benefit from their health data – with a special focus on marginalized communities."

The approach meant they needed to build an ecosystem. They also needed insights. They needed to form partnerships, conduct extensive research, and apply the latest medical advancements to address the unique challenges faced by the underserved populations.

Today NADPH operates in four key operational areas:

1) Research and Technology Development, in collaboration with medical and healthcare systems, including patient advocacy organizations to conduct research on health disparities. Research extends to the usage of patient and environmental data to prevent and treat disparities. NADPH develops health information platform to enhance data sharing and analysis capabilities.

2) Community Engagement with underrepresented and vulnerable communities to understand factors influencing their participation in health research and working with key stakeholders to develop ethical frameworks and recruitment models.

3) Patient Advocacy and thought leadership. In their work to provide community informed perspectives on the Community and Public Health Surveillance Data programs, NADPH has developed partnerships with the Robert Wood Johnson Foundation (RWJF) and the Centers for Disease Control and Prevention (CDC), to be at the forefront of the collection of community perspectives on public health data processes, and provides input to congressional representatives on proposed health legislation.

4) AI Infrastructure Capacity and Workforce Diversification. NADPH leads the National Institutes of Health (NIH) [Artificial Intelligence/Machine Learning Consortium to Advance Health Equity and Researcher Diversity \(AIM-AHEAD\) Infrastructure Core](#), where it provides under resourced and underrepresented institutions with AI infrastructure and computational resources to support

health disparities research, and also works with universities and technology companies through internship programs to foster workforce diversity in STEM and AI.

Dr. Carlisle recognizes that NADPH's outreach initiatives extend beyond conventional models of health research and are intended to create data, research, and implementation models that are more comprehensive and inclusive in scope. These initiatives better represent communities that bear the burden of health disparities and the factors that impact their health, and support the expansion of precision medicine-based practices to all communities.

"We actively engage with communities, providing tools such as AI driven data platforms to capture and integrate health-related information and resources. The goal is to make health information and data resources not only accessible but also comprehensible for individuals, ensuring they have the necessary tools to navigate their own health journeys."

NADPH is not immune to the challenges in developing more inclusive datasets that will disrupt a healthcare system that has failed to serve the more vulnerable populations.

There has been countless research in understanding the systemic biases ingrained in institutions, particularly in healthcare, whether it be [researching target populations](#) or [clinical trials](#). One critical aspect is the insufficient data available for doctors to accurately diagnose patients who haven't been well-represented in the system. This lack of diversity results in ineffective solutions, influenced by factors like age, geography, ethnic background, gender, and cultural specifics unique to different populations.

In addressing the sensitivity in this subject, Dr. Carlisle is clear that their intention is to prioritize building evidence-based understanding of the structural and institutional components leading to health disparities, emphasizing, "I believe in diplomacy, bridging gaps, and avoiding divisive postures. Rather than being painted into corners defined by societal dichotomies, I aimed to focus on common ground... The goal is to validate or dispel subjective perceptions and uncover the ground truth to arm individuals operating in the space with validated data to find more effective solutions."

### **The Supreme Court's Dissolution of Affirmative Action Sets Back Healthcare**

In June 2023, the Supreme Court's decision to end Affirmative Action has grave [implications for healthcare](#). The President of the [American Medical Association Expressed "concern"](#) stating, the decision is "bad for healthcare" and "undermines the nation's health, emphasizing that a diverse physician workforce is crucial for eliminating racial inequities. In addition, representation of marginalized groups in the healthcare workforce are keys to improving patient/physician relationships and health outcomes.

Dr. Carlisle points to the challenges in AI diversity, especially if college admission trends continue because of the ruling. It also hinders efforts to address health disparities and find solutions that promote health equity. NADPH has made significant strides in its work with Robert Wood Johnson Foundation, CDC, and NIH to assess communities' perceptions of data technologies and to work with them to co-design better AI solutions. There is concern that this ruling could threaten NIH's [strategic efforts to improve diversity, equity, inclusion, and access across the biomedical](#)

[research enterprise](#) to dismantle affirmative action in NIH programs, including the AIM-AHEAD initiative. As per Dr. Carlisle,

“NIH does not make funding decisions based on race; however, like other federal agencies seeking to follow national recommendations for increased diversity in science, technology, engineering, and mathematics (STEM) as a part of their strategic agenda to support an AI ready workforce, this ruling provides significant challenges to how they can articulate and positively affect that objective. This ruling has implications in AIM-AHEAD’s unique position to play a vital role in the national strategy to enhance our leadership in AI and innovation... These ambitions were grounded in extensive research assessments and recommendations from leading bodies like the [National Academies](#) and the [National Artificial Intelligence Research Resource \(NAIRR\) Task Force](#) highlighting the need for STEM diversification in technology especially among underrepresented communities.”

The [AIM-AHEAD initiative](#), initially designed to bolster the capacity of these communities to participate in and access AI technology, was given an initial \$100 million from NIH to address these needs. With the recent Supreme court ruling, AIM-AHEAD’s trajectory is now in question. Despite this setback, NADPH continues to lead efforts in AIM-AHEAD’s Infrastructure Core that are critical in providing AI infrastructure resources that incorporate community informed ethical and equitable principles, are co-designed and co-created with these communities, and that provide them with the low barriers for access and use that are necessary given their lack of resource and participation in this space. As per Carlisle:

“This infrastructure is vital in democratizing the capacity to conduct AI-based analyses of electronic health record (EHR) data that are focused on improving health disparities. To ensure the effectiveness of this technological advancement we will continue to adopt a ground-up approach by involving input from end users and community members as well as our continued rigor on comprehensive research to understand the needs of the community.”

NADPH also leads ethics and equity efforts to address the societal impact of AI. The goal, as per Dr. Carlisle, is to create a robust and highly informed AI ethics and equity framework, minimizing biases in technology development. NADPH’s findings have been shared through numerous publications and forums including [JMIR AI - Developing Ethics and Equity Principles, Terms, and Engagement Tools to Advance Health Equity and Researcher Diversity in AI and Machine Learning: Modified Delphi Approach](#); [An Expert Panel Discussion Embedding Ethics and Equity in Artificial Intelligence and Machine Learning Infrastructure: National Alliance against Disparities in Patient Health: Big Data: Vol 11, No S1 \(liebertpub.com\)](#) [Importance of Community Engagement in Data Decision Making | Big Data \(liebertpub.com\)](#) and [Special Session: Innovative Strategies to Engage and Center Community Voice and Infuse Equity throughout the Public Health Data Lifecycle \(confex.com\)](#)

### **Accomplishments Despite Adversity**

In the past two years, NADPH has achieved considerable milestones. One has been the establishment of a powerful [Persons with Lived Experience \(PwLE\) model](#). Through their research, they’ve been able to gain deep insights into community needs in order to inform development of technology that will maximize value while minimizing risk and harm. Dr. Carlisle continues,

“This model has proven its effectiveness through practical applications, for instance, in collaboration with the CDC Foundation, we undertook a project to evaluate data resources provided by the Centers for Disease Control and Prevention (CDC) within communities. The success of this project has underscored our expertise in quality assessment, attracting operational investments from organizations such as Robert Wood Johnson Foundation (RWJF)... who have been instrumental in advancing efforts in maternal and child health disparities.”

Through its work with RWJF, NIH, and others, NADPH has been able to introduce a platform designed to, not only facilitate data retrieval, sharing, and analysis from electronic health records and other sources across the health ecosystem, but also create broader access to artificial intelligence. Dr. Carlisle emphasizes that means community members, regardless of their expertise, “can develop, test and apply AI algorithms through an automated analysis engine... We’re still in development but we are actively expanding and reaching out, empowering communities with limited access to AI resources.”

As well, Dr. Carlisle points to their work in the Maternal & Child Health space with partners in Florida and North Carolina,

“These projects focus on increasing awareness and education about maternal and child health, and supporting pregnant and postnatal mothers with resources which aim to emphasize early detection and prevention of postpartum depression and suicide risk.”

As they look ahead, NADPH and its partners like Dr. Heather Flynn of Florida State, the [Florida Maternal Mental Health Collaborative \(FL-MMHC\)](#), and others continue to work with organizations like the Patient-Centered Outcomes Research Institute (PCORI) to actively seek support for these and other critical initiatives. The potential partnership with PCORI represents an important step in expanding NADPH’s impact in addressing disparities through innovation and community-driven approaches.

For Carlisle, NADPH’s evolution from the inception of the Harlem Personalized Medicine Institute to its current role as a dynamic force for digital equity has yielded significant successes, and forged important partnerships in the commitment to community-driven solutions. He is not immune to the setbacks from the Supreme Court Ruling ending Affirmative Action. Despite this, NADPH emerges as a significant player that has elevated the importance of restoring underserved communities, fostering data literacy and championing evidenced-based outcomes to advance its goals. Through early successes like the development of its PwLE model and community engagement and data resource (CEDR) platform, and efforts to support HBCUs and MSI build AI capacity, postpartum depression, suicide risk prediction and intervention in postpartum mothers, Dr. Carlisle and his team at NADPH are undeterred in their fight for the day when healthcare is truly accessible for everyone.

This is a poignant call to arms to alleviate the struggles faced by the most vulnerable in the communities. It’s a call to a profound commitment to community service, and a collective effort to ensure that technology does not leave anyone behind.

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