

ALVIN HATHAWAY SR.

Lessons From Baltimore for Participatory Research

A pastor and community organizer explains what a landmark Black neuroscience study needed to gain insight, influence, and credibility.

In June, a research article in *Nature Neuroscience* started to tease out why African Americans are more likely to get Alzheimer's disease and strokes and less likely to get Parkinson's disease. Using brains donated from more than 150 deceased Black Americans, researchers quantified each individual's proportion of European and African ancestry and correlated that with levels of gene expression. The study found ancestry was associated with different activity levels for genes related to immune response and blood vessels, but not for those related to neurons. The study also set the stage for exploring how different environmental factors—such as stress or pollution—can influence neurological health by driving changes to DNA that affect gene expression, part of the science of epigenetics. It is the first publication of the African Ancestry Neuroscience Research Initiative (AANRI), which I cofounded.

This is a landmark study in part because most biobanks, which compile biological samples for use in biomedical research, and analyses have focused overwhelmingly on people of European descent. As I wrote in an editorial accompanying the scientific paper, many large genome-wide association studies probing schizophrenia, Alzheimer's, autism, Parkinson's, and depression that included hundreds of thousands—or even millions—of subjects have failed to include a single Black person. (Indeed, many research analyses actively exclude data from minority populations for statistical convenience.) There's also a disparity in who does the research. Although 14% of the US population is Black, our representation is much lower among scientists. From 2010 to 2021, about 3% of research project grants awarded by the US National Institutes of Health (NIH) went to Black scientists.

In light of this, I want to point out that the establishment of AANRI signifies another, harder to recognize achievement: inclusive, participatory research. It is rare that the gowns of research universities truly engage with the towns they inhabit, but this initiative was born of an exceptionally tight relationship. It encompasses efforts from Baltimore community leaders, Morgan State University (the largest historically Black research university in Maryland), and the nonprofit Lieber Institute for Brain Development. And while there is still much more work to be done, I am proud to say that everything under the hood—from fundraising for the research to further building up Lieber's biobank and sharing results—has been achieved with respect, representation, and a comprehensive definition of community.

Here, I'd like to share my thoughts on what enabled this deep level of engagement, and what could foster it more generally. I will draw my account from my own experience but want to be clear that many people lent their expertise and passion to the research initiative, each with their own unique and essential contributions. The incomplete list includes Lieber director and CEO Danny Weinberger, Lieber scientific project manager Gwenaëlle Thomas, and advisor Kafui Dzirasa, who studies neuropsychiatric risk genes at Duke University.

A long beginning

The African Ancestry Neuroscience Research Initiative officially launched in 2019, but the seed sprouted when I happened to meet Danny Weinberger, head of the Lieber Institute, a couple years prior. I was serving on the board of a local development project with the Harbor Bank of Maryland

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IMO NSE IMEH, *Study, Residence of Evermore*, 2024 (1 of 2 panels), oil paint, India ink, acrylic ink, charcoal on unstretched canvas, 61 x 40 inches.

IMO NSE IMEH

MONUMENTS TO OUR SKIES



IMO NSE IMEH, *Journey to the Sun* (work in progress), 2024, oil paint, charcoal, India ink and acrylic ink on canvas, 50 x 72 inches.



During the summer of 2020—amid the pandemic, lockdowns, and widespread displays of racially motivated violence that appeared on screens across the United States—artist Imo Nse Imeh was deeply engaged with questions of faith, trust, belief, and redemption, particularly in the context of Black communities. *Monuments to Our Skies* is the result.

Each canvas in this series offers a unique combination of material and form. For Imeh, the choice of materials is crucial, as it influences both the process and the level of control he can exert. He often begins with India and acrylic inks, applying them to the unstretched canvas in dynamically more and less controlled sweeps of color that can be both additive and destructive. He then uses charcoal and graphite, simple yet powerful materials that can tell complex stories and exhibit an immediacy unique to drawing and draftsmanship.

From these materials, Imeh creates both figures and what he calls “bio forms”: structures and patterns from which the figures emerge and into which they can disintegrate. He does not view the bio forms as merely abstract; they are a direct product of his drawing process, making them concrete and real. As he puts it, they are “elements of things that are alive.” Like the bio forms, the figures are more than representations or abstractions; they are ways of seeing the mind at work, a channeling of memory and thought through the actions of the artist’s hand and eye.

Imo Nse Imeh is a Nigerian American visual artist and scholar of African Diaspora art whose work explores historical and philosophical issues around the Black body and cultural identity. He is a professor of art and art history at Westfield State University in Massachusetts. Imeh has made contributions to the visual arts discourse through publications, lectures, exhibitions, and thought-provoking studio art projects that interrogate the ways Black bodies are imagined, ritualized, and transformed.

The exhibition *Imo Nse Imeh: Monuments to Our Skies* will be on view at the National Academy of Sciences, 2101 Constitution Ave. NW, Washington, DC, from February 3 through July 1, 2025.



IMO NSE IMEH, *Harvester Angel*, 2022, charcoal, India ink, and acrylic ink on canvas, 48 x 48 inches.

that made loans to projects deemed to bring value to the community. One such project we funded was a complex at 855 North Wolfe Street in East Baltimore. I decided to visit and see it for myself. That's when I realized that the anchor tenant was not a grocery store or even a business, but a nonprofit research institute. I wanted to learn more.

This brought together many of my own interests: I was already a long-term participant in an NIH study on aging, in part because I appreciated the intense medical workups, and in part because I knew African Americans were underrepresented in research studies. I've been serving in Black churches since my earliest youth. Back in the late 1970s, I was part of a consortium of faith-based communities, Baltimoreans United in Leadership Development, or BUILD. For me, participating reinforced the importance of faith-based organizations and community organizing. In the 1980s, I became the executive director of the Southeast Vicariate Cluster of Churches in Anacostia in Washington, DC, where I explored how faith-based communities could play a role in health care delivery. I'd worked with seniors in health care facilities who didn't have anyone to look out for them, and helped create an ombudsman program between churches and hospitals. At the time, the Southeast Cluster had funds from the Robert Wood Johnson Foundation to train people to look for warnings of ill health in frail and isolated members of their community. It was my first experience of a research grant. But even before that, I had been sensitive to issues of quality of care, as my family sought programs to help my older brother and soulmate, Charles, who would now be recognized as extremely autistic. He had a network of services available—but only if one knew how to seek them out.

Baltimore itself has a particular relationship to the medical research establishment that goes back generations and includes what might be described as both the best and the worst. In the realm of the best, consider neurosurgeon Ben Carson, famous for separating twin babies joined at the head, and cardiology pioneer Levi Watkins, who was the first to implant an automatic defibrillator. Both worked at Johns Hopkins University and helped form the many ties between that institution and the wider community. But Johns Hopkins is also where Henrietta Lacks sought treatment, and where her cells became part of globalized research without consent or compensation. And the memory of the community goes back further: one of my congregants had an uncle who was part of the infamous Tuskegee syphilis study.

This history meant that when I met Weinberger, I was ready to speak the researcher's language—but I was not going in with rose-colored glasses. I soon learned about the care and sensitivity Lieber staff took when obtaining human remains to get consent from next

of kin, working across four medical examiners' offices. I learned that they had thousands of frozen brains donated by individuals and family members who hoped their bodies could aid science and lead to improved care. This had been on my mind when Charles passed in 2012. Weinberger told me they had biological material to study neurological diseases in African Americans specifically, but said there was no funding to carry it out. That fact stuck with me.

I had friends in state and national government and was able to lend my influence to make sure African Americans were included as genomic mapping projects were deliberately extended beyond those of European descent. I was also able to make a case to the Abell Foundation, dedicated to improving health, economic, and educational outcomes in Baltimore City, that they should help to finally unlock insights from the African American brains housed in Lieber's biobank. More donations followed their lead.

Community and credibility

But it takes more than funds to create a true community project. So often community is overly circumscribed: perhaps a researcher considers only his or her lab or the larger university. Having been in ministry nearly three decades, I am naturally inclined to think of my community as my congregation and their families. (Congregants say I either hatch them, match them, or dispatch them.) But the AANRI went beyond Lieber and my congregation: the inclusion of Morgan State University brought insight, power, and credibility. Dedicated funding now supports collaborations between Lieber personnel and Morgan faculty, plus student internships and faculty training at the Lieber Institute.

Lieber leadership also brought in Gwenaëlle Thomas (who'd earned her PhD with Kafui Dzirasa at Duke) as scientific project manager to cement Lieber's commitment to community and cross-institutional collaboration. This helped secure hands-on research programs for Sollers Point Technical High School outside of Baltimore and enabled the development of an applied neuroscience graduate program at Morgan State, where Thomas and other Lieber Institute colleagues also teach neuroscience courses.

When I see a community, I see it through the lens of anchor institutions. These are often faith-based institutions or local universities. They are populated by people, of course, but they have intergenerational stories. My mother's youngest sister graduated from Morgan State University in 1944, and she told me about the protests students held for equality in the parking lot—long before the more famous civil rights demonstrations in the 1950s and '60s at the same school. These institutions have long-standing narratives—in the case of Morgan State, three generations in just my own family—meaning they have both credibility with their communities and a responsibility to them. If I am looking for participatory research, I am first going to identify the anchor institutions.

Even with my long experience in community organizing, perhaps the most surprising thing I've realized is how important it is to push yourself for an expansive definition of community, because essential members of your community may not be the people that you see every day. If you neglect to do this, it's like playing a game of chess without putting all the pieces on the board. Done well, it's a vibrant ecosystem where well-allocated talents yield more and more, constantly seeding mutual interests.

Lessons expand

Once the community is acknowledged, four principles come into play. I call them *the four Rs*: recognition, respect, relationships, and results. I first articulated these in a book chapter on community planning and resilience in 2004, and my experiences since have only confirmed their importance.

By *recognition*, I mean realizing that there are subject-matter experts within your community, and that those subjects can vary greatly—as can the formality of their training. One of my congregants alerted me to the NIH aging study and how important it was that data on African Americans were included. Consequently, my wife and I enrolled and participated for over a decade. The congregant had been participating for many, many years before I ever knew about it. It sounds trite, but just getting to know people better can put the expertise you need in your path. This has happened to me time and again. But recognition means more than seeing the expertise within people; it also means having a sense of who people are, what's important to them, what they struggle with, where they find joy. So often in research, academics consider just the neighborhood where an individual lives; they don't probe all the connections—to sororities, say, or churches, or other groups. Community organizers know to look at all the connective veins that reveal people's interests.

Recognition is closely related to *respect* for expertise and how that expertise can lead to the success of an enterprise. Efforts prove more effective when the assumption is that people are competent, their ideas relevant, and both their needs and values worth meeting. The requirement for respect may be the most obvious in failures: a research study gets no volunteers because enrollment sites are inconvenient and the premise irrelevant to a community. Respect also means understanding different stakeholders' pressures and realities. Patients might get impatient with the slow pace and ambiguity of research. Initially, Weinberger thought his job was to assure community members that he was doing good science, but he realized he needed to persuade them of something more visceral: that he wasn't out to make anyone look bad. Community members also need assurances that the time and insight they share will not add too much burden to their already overfull lives, and that their contributions will improve a community that they care about.

Underpinning both respect and recognition are *relationships*. Too often, potential collaborators go straight to the task and overlook the person. But skipping over the relationship weakens collaborators' ability to focus on the task. That doesn't mean collaborators should be best friends and confidants. It does mean that the relationship needs to be more than transactional while also being mutually beneficial. If we don't take the time to understand all the connections of people coming into research, then there is no scope for mutual self-interest, for selves intersecting. And then the relationship becomes limited, shallow, and fragile, reduced to transactions. When a deeper relationship exists, it is easier to move beyond transactions, because each interaction is just one of many events in something that is understood to be ongoing.

My relationship with Bob Embery, head of the Abell Foundation, is an example. When he decided to put in seed funding for AANRI's project, it was a risky move for his philanthropy, which traditionally focuses on community development. But we already had several points of connection. We graduated from the same high school, many years apart, and knew of each other's long histories of community work through various organizations. We had reached the point where we would bounce ideas off the other informally, so when I approached him about AANRI, he was ready to both share his skepticism and trust my instincts. He knew that our relationship benefited each of us, was based on shared goals of improving the quality of life for citizens of Baltimore, and would endure long past any single funding event—in part because we each knew how to say “no” to the other. Our relationship is not a one-off series of transactions; it is an ongoing exchange, the majority of which (including AANRI) has paid off in real results toward our shared goals.

The fourth R is *results*, because something should come of relationships, of people working together. I have compared achieving results to rounds of three-dimensional chess. The philanthropic and academic sectors often exist as silos. As a community organizer, I think about merging silos and making sure that everyone is playing the same game. The question is how to get people to agree to a particular course of action, and determine what is needed to catalyze it. Once people are working together, I busy myself communicating with many different stakeholders.

It's crucial to understand that none of these principles can be achieved overnight. The process can be recursive, with results amplifying as projects continue over the years and expand to other communities. And that's what inclusive research is asking for. With enough communication and commitment, competing interests are brought to heel, mutual interests flourish, and broad benefits abound.

Alvin Hathaway Sr. is cofounder of the African Ancestry Neuroscience Research Initiative and pastor emeritus of Union Baptist Church in Baltimore, Maryland.



IMO NSE IMEH, *Untitled*, 2024, charcoal and acrylic ink on canvas, 36 x 36 inches.