



After the Fact | Race and Research: [The Gaps in Health](#)

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TRANSCRIPT

Dr. Marie Bernard, chief officer of scientific workforce diversity at the National Institutes of Health: *It is important to recognize that when we talk about health disparities, minority health, health equity research, it's not just because it's the right thing to do. It's because it allows you to see the problem more clearly scientifically.*

Dan LeDuc, host: Welcome to "After the Fact." For The Pew Charitable Trusts, I'm Dan LeDuc and that was Dr. Marie Bernard of the National Institutes of Health. We'll be speaking at length with her in this episode.

[Transition music]

The coronavirus has had a disproportionate effect on people of color and exposed long-standing inequities in health care and research. In this third episode in our look at race and research, we're turning our attention to the role of diversity in medical care—from the patients to the doctors and to medical research. Let's begin as we do every episode, with our data point—the Pew Research Center reported this year that only 5 percent of the doctors and surgeons in the United States are Black, while Blacks make up 13 percent of the population. That shortfall, says Dr. Bernard and other experts, creates issues of trust between patients of color and their doctors. Likewise, medical studies which frequently in the past did not include enough people of color or failed to take into account patients' living conditions or diets means researchers haven't always had the full picture of a range of ailments from Alzheimer's to high blood pressure.

As you'll hear, there are efforts now to change that. Here's Dr. Bernard.

[Transition music]

Dr. Marie Bernard: Diversity matters because we have really good evidence that when you have diverse groups of people working on various problems, you end up with better answers, more creativity, more innovation. So it's really important to us to make sure that the workforce that is trying to solve the nation's health problems is a truly diverse workforce.

Dan LeDuc: So how did the National Institutes of Health begin to even discuss this problem, begin to work on this problem. Is this a recent thing? Or has there been a recognition, maybe over time, about the need for this.

Dr. Marie Bernard: So the National Institutes of Health has focused on issues with regards to diversity for a while now. There have been policies in place to assure that there's diversity of participants in various clinical studies. In 2011, when Donna Ginther



and colleagues did an analysis of the success rates of various groups that are usually underrepresented in science, getting grants from NIH—what’s called R01-equivalent grants—they found that the various groups tended not to have the same success rate as non-Hispanic Whites.

And in fact, when you controlled for all sorts of factors—English as a first language, education, institution a person came from—that there was a persistent disparity in receipt of these R01-equivalent grants for African Americans and Blacks. So prior to those controlling factors, Hispanics, Asians, American Indians, Alaska Natives, all seem to be at a disadvantage. But there was that persistent disadvantage that was seen. And thus the NIH director, Dr. Francis Collins, turned to his advisory committee to help to think about how to address this issue. And the advisory committee came up with a number of recommendations. One of which was to establish this role of chief officer for scientific workforce diversity. I’ve been privileged to step into that role as of Oct. 1, 2020.

Dan LeDuc: If I could, I would like to just ask you a little bit about your own personal experience. You’re a woman of color who entered this field. Tell us about how you got interested in medicine, maybe the challenges you had initially. And how do you think your personal experience has influenced the work you’ve done.

Dr. Marie Bernard: I went to college planning to be a French major. But my French with an Oklahoma accent didn’t cut it. But I did really well in chemistry. And ended up saying this is the direction that I want to go. This was as things were beginning to open up for women and for people of color. So that when I entered medical school I was in the largest class of women at University of Pennsylvania to that point. And as a result, you run into things because you’re the first. I would, frequently when I walked into a patient’s room, be mistaken for the nurse or the ward clerk.

So I would routinely say “Hi, I’m Dr. Bernard,” before they had a chance to make the mistake. I would frequently be singled out for questions. Because it’s no hiding, I was different from the rest of my classmates. But that made me stronger and better, I felt. I do know that there continue to be microaggressions that people have to endure. And unfortunately sometimes there are still overt aggressions. And we need to continue to work to eliminate those sorts of things.

Dan LeDuc: I was struck by a phrase on the website of your initiative, at the NIH. We we’ve all heard that expression great minds think alike. And you guys have added the phrase great minds think differently. You’ve mentioned there’s data and research that supports that notion. Could you go a little deeper on that and help us understand that.

Dr. Marie Bernard: I’m happy to talk about the data that shows that diversity makes a difference. There’s a lot in the business sector. And there’s a growing amount in the scientific sector. In the business sector, you can for instance, have individuals involved in mock reviews for law review and evaluate the quality of the decisions that are being made. And demonstrate that when you have a diverse panel versus a fairly homogeneous panel, there’s more information that’s brought in that could be considered the ideal approach to the problem.



When you look at people who have done work in the stock market and look at homogeneous teams versus heterogeneous teams from a diversity standpoint, the more homogeneous team ended up paying more and getting less return on investment than the heterogeneous team. It's kind of almost like there was a group think of the homogeneous group. So they drove up the prices and paid a lot more for the stock than they needed to.

In the scientific arena we have research that demonstrates that when you look at the diversity of a scientific team—whether you're looking at that diversity based upon seemingly race ethnicity, based on name or looking at diversity based upon the geography of where individuals come from, or look at diversity based upon the number of other citations that they've brought into their planning—the research leads to publication that is more impactful when you have a diverse team versus a very homogeneous team. And that seems to be over and over again that we're able to demonstrate those sorts of things.

Dan LeDuc: How do we get started on the workforce?

Dr. Marie Bernard: When you start looking at children in high school, you see great diversity in the population and great interest in science. What we are running into, however, is that at every stage on the pathway to becoming a scientist, those numbers and percentages go down.

So that you may start looking at people at the community college level as they're entering a great deal of interest in science. You look at people at the point at which they become a director of a department, or what's considered a senior scientist. And there's very little variety in the people who were there. And at every step of the way, there have been decreases. What we know as well, however, is that the sorts of questions that people ask in science relate to what their personal experiences have been and their interests are. And those are going to vary. For instance African American and Black scientists, almost half of them focus on topics that are in a very circumscribed area, much of it being health disparities, health equity, minority health research. And all of those things are helpful to us to get a sense of the total health of the nation. So, for all of those reasons, the decreasing numbers over the course of time, the importance of the questions that are asked, you need to have a variety of people at the table.

Dan LeDuc: For more than a year, Dr. Stephanie Brown has been contending with these issues at patients' bedsides. She is a second-generation physician, African American and an emergency clinician at Sutter Health, which operates two dozen hospitals and more than 200 clinics in Northern California. Sutter traces its founding back to the response to our nation's last pandemic, the 1918 Spanish flu.

Dan LeDuc: So let's talk about now as a practicing physician what you're learning about some of the struggles that communities of color face as they're trying to get medical treatment and health care.

Dr. Stephanie Brown, clinical lead (lead physician), Sutter Health Institute for Advancing Health Equity: So what you see is really it's going back to the social determinants of health. The conditions in which we're born, we live, we work. And those



are the conditions that inform how we are going to experience health and health care. And really inform our health outcomes as well. If we think about our society, American society, there is a long-standing history of structural racism that's built into the fabric of this nation. And that plays out in access to health care. If you think about educational policies in this country, and the limitations that people of color have in terms of equitable education. Within our medical profession, we don't have the same representation as Whites do. Studies have been done that show that racially concordant care, meaning getting care from someone who looks like you from your community, leads to better and improved health outcomes. And better patient satisfaction as well, which is huge.

Dan LeDuc: There's actually research you were citing that says if your doctor looks like you, you're likely to have better health outcomes just because there's a greater bond of trust.

Dr. Stephanie Brown: The more trust you have in the plan, the more likely you are to be successful at it. Think about the fact that Black women make up only 2% of the physician workforce in this country. The studies have shown that when women have OB-GYN physicians' representation on the health care team that's racially concordant, you have lower C-section rates and better health outcomes. If you look at a map, and you look at where people live, and then you overlay it with where the hospitals are and the clinics, you sort of get your answer. And then you take it further. Look at where the pharmacies are. How do you get your prescriptions? And so on and so forth. And so health disparities are a natural product of a structurally racist society. We're seeing disparities play out in every way.

Dan LeDuc: But there's work to be done: Last year, the Pew Research Center reported that 35% of Black adults had a great deal of confidence in medical scientists to act in the best interests of the public, lower than when compared to Whites at 43% and Hispanics at 45%. Dr. Bernard has had her own experience in working to develop trust among communities of color and says the NIH is going to be doing more.

Dr. Marie Bernard: Trust is a big issue when making outreach to the African American community, the American Indian community, and others. And it's something that is hard won and easily lost. And we have a very poor track record, unfortunately here at NIH. In terms of what happened with Henrietta Lacks, what's happened with research in American Indian populations with diabetes. So during this pandemic, NIH has been very cognizant of that. And we've developed a couple of initiatives, something called RADx, something called CEAL, to focus on underrepresented populations, to develop outreach to those populations. But you can't just all of a sudden make that happen. You have to work with people who are already embedded within those groups who can be ambassadors, mediators, that sort of thing.

When I was a young faculty member at University of Oklahoma—I grew up in Oklahoma—my childhood friend, who was a faculty member at another university in the area, and I decided we were going to go and do research among the African American population that lived just off of the OU health sciences campus area. I had grown up in that area. And we were going to do this study on nutrition and function of the population. And even though we were African American, making outreach to African Americans in the neighborhood where we had grown up, they were not welcoming to us initially



because we were part of the establishment. So it's a matter of developing those relationships. And there are some general principles and then all things local.

Dan LeDuc: Well based on that experience and what you've learned over your career how do you go about regaining trust?

Dr. Marie Bernard: The tough part of building trust is it takes time. And it takes energy. And it's really kind of a one-by-one sort of thing. My example with the African American community, my colleague and I sat and met with representatives of the senior living complex. Asked them "What are your needs?" Their response was, "People come in. They do research. And we never hear from them again." Or, "I'm not sure exactly what your research is and I'm not sure that it's safe. Or, "We need things and we never get anything." And similarly with the other initiatives, you have to sit down, you have to listen to what the group has to say and address it.

Another outreach I made when I was in Oklahoma was to Native American populations. We had lots of Native American populations there. But you don't just traipse into the tribe and start doing research. You talk with the tribal council. You talk with the tribal elders. You make it very clear what it is that you intend to do. You find out what their expectations are in terms of communications. It's a long process. And it is very much enhanced by having someone who lives within the community who is going to be your surrogate. To say this is a person that you can talk to. This is a person who is going to be trustworthy.

Dan LeDuc: Back to Dr. Brown on how this trust has played out over the past year, while she was on the front lines treating COVID-19 patients.

Dr. Stephanie Brown: The very first extremely ill COVID patient that I had was an African American man. And thinking about all of his comorbidities—diabetes, hypertension, on dialysis. All of the things that we know that people of color suffer at higher rates. And that just shook me to my core in many ways. The inevitable outcome then also being that he would have more severe disease and at a higher risk for dying. And plays out individually with each patient as well as in our research. We didn't know what we were dealing with at first. And trying to keep up with the data, and trying to keep ourselves healthy. It's just a really big task. Trying to build trust in a place where we didn't even know what we were doing. What I will say is that it's just a more emotional experience looking a person in the eyes.

Dan LeDuc: I can only imagine. And you brought up that word trust. So what's been the trust factors that you've been running into with some of the patients of color you've dealt with? Is there some skepticism? Some concern about the treatments you're talking to them about?

Dr. Stephanie Brown: Lots of care has shifted to virtual visits. And when we talk about access to care, people don't necessarily know how to or are even able to navigate the technology. So just even before you get into how people feel and the differences in dynamics between patients of different races, you have to consider that it's just hard for anybody to establish trust when they're sick, they don't feel well, and they can't even see you and make eye contact. And so going further, if you have experienced the health care



system in a way in which you're sick—you have diabetes, high blood pressure, renal disease, heart disease—you are already interacting with this health care system for a long time in specific ways. And so people bring that with them. They don't check that at the door when they come into the emergency department. All of that comes with them.

Dan LeDuc: All the issues that patients contend with ideally would be in their electronic health record, the computerized version of the old paper medical chart that used to be clipped to a hospital bed. Here at Pew, there's a project that is working to increase the benefits of those EHRs, as they're called, by seeking standardized ways for patients' data to be documented and ensuring that the many computer systems that hospitals and doctor's office use are able to talk with each other. Sutter Health also wants to see those records enhanced with more information about patients that can provide new insights into their health—things like where they live and what they eat. Kristen Azar is the scientific medical director at the Sutter Health Institute for Advancing Health Equity.

Kristen Azar, scientific medical director, Sutter Health Institute for Advancing Health Equity: The electronic health record originally was intended to really replace paper records and was meant to be used in one-on-one clinical encounters and visits between the clinician and the patient to capture important information about that person's care and their care delivery. And since that has happened, we really evolved our thinking around the use of the EHR as a tool for population management, for public health and medical research, and for, really, programmatic planning within health systems. And the EHR really has unrealized potential to make an impact on these big public health problems and these big complex issues that we're seeing in terms of health inequities and disparities within minoritized and marginalized communities. And some ways that we see that is with the collection of social determinants of health data that really have been missing. For example, access to food and housing and your occupation, that all impacts your health care, and your health outcomes. Within Sutter, we are working on implementing a standardized approach to really getting some high-quality data into our system to be able to use that to inform not only the opportunities for intervening to improve health care and the disparities that we identify, but also to inform solutions that can then be developed to then address those disparities in collaboration with our community partners and our internal stakeholders as well.

Dan LeDuc: Once you start putting electronic health records together, all of this other important data that determines health can be added to these records. Are we at the beginning of maybe a new phase of research on social determinants of health? It feels like this would offer a huge dataset.

Kristen Azar: I'd like to think we are. I think we've been moving towards this point for some time and are continuing to evolve in the way that we think about the potential for using EHR data for this purpose and for medical research and public health research.

Kristen Azar: I think there's a fine balance between really wanting to make sure that we are obtaining high-quality data that can really be used to achieve the goals that we have for understanding our populations, programmatic planning, addressing disparities once we identify them. That all requires really robust data collection that can be easily extracted on the back end and then analyzed, whether with analytics and informatic



teams. And so having conversations with our staff, with our providers, with our clinicians, our leaders within the health system to really help them to understand the potential that this information has to really change the way we deliver care and to really close those equity gaps. And some of these questions may not be comfortable. And they may bring up issues that are really sensitive. And so really keeping that in mind when we talk to our patients or when we design these surveys or these processes is important.

For example, early on in the pandemic, we saw that there were disparities emerging among communities of color, among Hispanic, Latinx community, and also the Black community.

Race is an imperfect proxy, but does give us an understanding of some of the differences that we were seeing among our patients in terms of outcomes. And so having that knowledge and having been able to use that data in that way, we can now inform our vaccine equity distribution efforts to think about how we can incorporate ideas around equity in setting targets for outreach and for resource allocation.

And it's important to make the distinction that equality and equity are not the same thing. So equality is really giving everybody the same treatment, the same services, whereas equity takes into account that disproportionate burden of disease and death and illness.

Dan LeDuc: And specifically, it allows, maybe in ways that hadn't been happening before, to address issues for communities of color.

Kristen Azar: I think, really, the advent of the EHR to be able to hold this amount of data and to be able to organize this data in a way that can easily be extracted and then looked at for population health research has been huge in moving that, this effort forward. And I think people are asking more questions about race and about race ethnicity and the role that it plays in people's health and racism and structural racism and how all of these types of important pieces of information about social determinants of health really do complete the picture of how populations and patient groups get, are minoritized or marginalized and the role that those pieces really do play in the health care that they receive, the access, and also the outcomes. And so I think asking more questions and wanting to understand the fuller picture is really driving the need to think about the types of information that we capture at the individual level that can then be utilized at this greater level when it's joined with the individual data from millions of other people.

Dan LeDuc: And for Dr. Marie Bernard, taking on these issues is not just about solving disparities but improving care for everyone.

Dr. Marie Bernard: It is important to recognize that when we talk about health disparities, minority health, health equity research, it's not just because it's the right thing to do. It's because it allows you to see the problem more clearly scientifically. A great example of that: One of the hats I wear is as deputy director of the National Institute on Aging, and we lead for the federal government research with regards to Alzheimer's disease and Alzheimer's-related dementias.



And much of the research in the early years was done on very homogeneous populations, generally a high socioeconomic status level, non-Hispanic Whites. And we've been able to discover that there are a lot of genes that are associated with the development of Alzheimer's disease. However, as we have broadened the participation and brought in Asian populations and Hispanic populations and African American populations, we found many more genes that are associated with Alzheimer's disease. Giving us the hope that with this broadened group of genes that we can look at, we will find a means of preventing or treating this illness much more rapidly than when we had the more restricted panel that we were looking at.

So it is the just and right thing to do. It does lead to greater creativity and innovation. And that creativity and innovation is applicable to all, at least generalizable principles, a much better understanding of whatever disease you're concerned with.

[Music plays underneath Dr. Marie Bernard's final statement]

We are really aiming to change the things systemically, that serve as barriers for all individuals who are not well heard currently in science.

And I am hopeful that we will, in the end, have new systems in place that make sure that every voice is heard regardless of position, of viewpoint, the dominant paradigm. I think we're well on our way in that direction.

[Transition music plays in full]

Dan LeDuc: Thank you for listening. You can learn more at pewtrusts.org/afterthefact. We're continuing our look at race and research in our next episode as we turn to race and economics.

David Williams: *Our research shows that kids who are growing up in the same communities have very different outcomes based on their race and ethnicity.*

Dan LeDuc: Until then, I'm Dan LeDuc and you're listening to "After the Fact" from The Pew Charitable Trusts.