

Dr. Monica Webb Hooper
Behind the Mask
December 23, 2020

Barr: Good afternoon. Today is December 23rd, 2020. My name is Gabrielle Barr. I am the archivist at the Office of NIH History and Stetten Museum and today I have the opportunity of speaking with Dr. Monica Webb Hooper. Dr. Webb Hooper is the Deputy Director of the National Institute on Minority Health and Health Disparities and today she will talk about three of her COVID-related activities as she does very many things in her role at NIH, so we will focus on three. So, thank you very much for being with me today and talking about some of your experiences.

Webb Hooper: Absolutely. Thanks for the invitation.

Barr: So, to begin, you've been doing a lot of work on NIH's products initiative. Can you, briefly, describe what the RADx [Rapid Acceleration of Diagnostics] program is, what its objectives are, and whom it is designed to serve?

Webb Hooper: Sure. The NIH Office of the Director committed half of its one billion dollar Congressional appropriation for COVID-19 testing research, that is 500 million dollars to focus on underserved and vulnerable populations. This is the major initiative that we refer to as Rapid Acceleration of Diagnostics – Underserved Populations or RADx-UP. And I think it's also really noteworthy that this is, to my knowledge, the largest NIH investment in health disparities research for a single initiative.

This is a new consortium of community-engaged research projects that are focusing on increasing access and uptake of COVID-19 tests. This consortium will generate data from these projects that will help us understand disparities in infectious disease transmission and outcomes, and it will be really useful for evolving the science on strategies to reduce disparities, through the use of FDA-authorized diagnostics. Importantly, RADx-UP is also focused on the social, ethical, and behavioral implications of testing underserved groups. So, we will be studying what happens when you test underserved populations, what are the next steps that we should be thinking about, especially among individuals who may not have the privilege of being able to self-isolate. How can we make sure that patients interpret their test results correctly? So, this is a really significant initiative and it is the one component of RADx, overall, that is focused on increasing access.

Barr: So, there are many underserved and vulnerable populations in the United States, unfortunately. Are there particular groups or communities that this project is focusing on?

Webb Hooper: Absolutely. RADx-UP is prioritizing those populations that are underserved, including racial and ethnic minority groups, sexual and gender minorities, socioeconomically disadvantaged populations, and underserved rural communities, as well as populations that are COVID-19 vulnerable due to medical, geographic, and social factors, including pregnant women and children, individuals with medical comorbidities, older adults, homeless populations, persons with

disabilities, individuals with substance use disorders or serious mental illness, migrant communities, residents of tribal lands or reservations, and many others.

Barr: That is quite a lot. What actions have you taken to reduce disparities, and have you tailored how you have interacted with these particular groups in individual ways?

Webb Hooper: It is a great question and I think the answer is that RADx-UP is a new initiative so we are learning as we go, and the goal will be to generate data that really helps us understand the appropriate and effective actions to reduce health disparities with testing as the primary component, and then understanding the cultural and community nuances and needs for tailoring that we don't yet have the answer for. We know about this from research in other areas, but because COVID-19 is an unprecedented situation, and there are lots of factors that are influencing one's access and uptake for testing, we will be learning a great deal about the actions that need to be taken to reduce these disparities. You know, when you think about that, we are unsure what the trajectory for COVID looks like, and when we will be on the other side of this pandemic, and when people will be vaccinated, but testing will always be an important part of this condition as long as it exists. So, we think this is a really important initiative, and we are confident that we'll be learning a lot of information that will help us not only to address health disparities as it relates to COVID-19, but we think it also provides an important window of opportunity to understand strategies for addressing health disparities that have existed for decades, and longer than that, in a way that is meaningful and impactful.

Barr: Is it too early to assess what are some things that you and others working on this initiative have learned so far?

Webb Hooper: Well, I think there are lots of things that we have learned thus far from observational data. I developed a model that helped me think about the factors that contribute directly to COVID-19 cases and outcomes. I think that COVID-19 is illustrative of the overarching health disparities in the United States more broadly, so, in this model we can theme the factors as being related to health and healthcare, socioeconomic, and social determinants of health, and we cannot ignore the backdrop of systemic inequities which are also associated with poor health outcomes. Some of the factors that we might think about are housing insecurity and food insecurity. Much has been reported about racial/ethnic minorities being employed in essential jobs that force exposure to the virus, and to give one example among nurses, who are mostly women, nurses of Filipino descent comprised just about four percent of the U.S. workforce, but nearly a third of registered nurse deaths due to COVID-19. This represents the largest racial/ethnic minority group to die of the disease within this workforce, followed by African American nurses. So, we have learned that COVID-19 racial and ethnic disparities are driven by differences in exposure. There are structural issues that are taking place here rather than biological or genetic factors.

Barr: That's interesting. I know that RADx-UP has different phases of it. What phase are you currently in with this program?

Webb Hooper: We have made great progress in record time with RADx-UP. We have completed the awards for phase I of this initiative. Phase I consisted of three funding opportunities, and then an

opportunity for a large coordination and data collection center. Two of the mechanisms were testing research projects. These are the projects that are focused on how we can increase access and uptake of testing, getting testing completed in as many populations that we prioritize as possible, and so we have awarded 30 sites that are large networks and research centers who already have established relationships within communities and with community organizations. We also funded smaller individual grants to conduct testing research projects, and we awarded 23 of those, and then we also awarded 16 grants that are focused on the social, ethical, and behavioral implications of testing. These, combined with our coordination and data collection center, which is a large, very large, grant, that will manage this consortium over the four years – is a total of 70 grants awarded in its first phase, and we are starting the process of planning for phase II.

Barr: What will phase II encompass?

Webb Hooper: Well, phase II is expected to be an extension and expansion of phase one. We will be in 2021 developing funding opportunities that adjust for the changed landscape. Everything with COVID-19 changes week to week and when we developed the opportunities for phase I, there were not FDA-authorized vaccines on the horizon. Now that we have vaccines that are approved or that are authorized and there might be other vaccines that are also approved, we have to factor in how that will relate to this landscape. There are also new testing technologies and we want to understand how we can incorporate them and provide access, in effective and culturally responsive ways, to our communities. So, as we move into planning for phase II of RADx-UP, we will be thinking about and planning for the future in terms of how we can ensure that diagnostic testing for COVID-19 remains a priority, but also adjusting for the changes in the landscape.

Barr: Yes, definitely. So, with this initiative, what has it been like to work with researchers as well as with community organizations? There have very different needs and mentalities, I am sure.

Webb Hooper: Well, you are correct, and as a community engaged scientist, I greatly appreciate this question. In my experience working with community stakeholders in terms of the meaning and the richness of research, from where I sit the significant involvement of stakeholders at all levels and disciplines, and community organizations as well as lay community members, is a must in the context of research among underserved populations and so, this has been a cornerstone. Community engagement and community engaged research are cornerstones of the RADx-UP initiative.

Barr: Can you speak a little bit about how you have been involved personally with this initiative?

Webb Hooper: Sure. I have had the honor and the privilege of serving as a co-chair of the RADx-Up working group. My co-chair and I have really been involved from the beginning to help design this initiative, to help bring the various staff who are working across NIH together to work on the development of the funding opportunities. So, I had— especially starting at NIH when I did, which was just as the pandemic started—it was really an amazing opportunity for me to be able to infuse my voice as a community engaged scientist, who is focused in my research program primarily on racial and ethnic minorities and other underserved and under-resourced communities. I was able to bring that perspective into this initiative in a way that I hope was helpful, and I hope is going to be impactful in the

science that results from this. Our working group was a highly engaged group of program and other staff from across NIH, who came together and worked diligently over a period of months to develop four funding opportunity announcements. We managed the review process, we managed the webinars that were the launch pad for this consortium to really take shape, and many of these folks are going to be involved as we move into phase II.

Barr: What was it like, the timeline between when you first starting to draft these notices to getting them out there?

Webb Hooper: The timeline was short. We had deliverables and we had to produce funding opportunities as quickly as possible given the urgency around this pandemic. We started at the end of April and our first funding opportunities receipt dates were in August and then September, and we completed the funding for phase I in early November so, it was a short time frame to bring a 500-million-dollar initiative together.

Barr: Yes, definitely. What has been the biggest challenge so far with working on RADx-UP?

Webb Hooper: I think that the challenges have really been mostly about making sure that we could develop a quality product in such a short time, and at the time that we started the initiative there was not much that we could derive from the science because there were so many unanswered questions, very few publications with peer-reviewed findings that we could draw from. That was one of the challenges; we had to often draw from what we know about health disparities in general and apply it to what we could observe what is happening with COVID-19. I think that what we ended up with was a really strong, robust set of applications and a set of projects that are going to make for a consortium that is like none that we have ever seen, that are all focused on the same goal. We are excited and we expect to see rapid impacts from these projects that can hopefully lead to longer-term solutions.

Barr: Yeah, definitely. I think we are going to move on to another initiative that you are involved with—the CEAL [Community Engagement Alliance] program. What has been your role in NIH's CEAL initiative?

Webb Hooper: CEAL is the NIH Community Engagement Alliance Against COVID-19 Disparities, and I have the honor and privilege of co-leading the program team. This is an initiative that is co-led by the NIMHD director Dr. Eliseo Pérez-Stable and the NHLBI director Dr. Gary Gibbons. They are the co-chairs of the initiative and I co-lead the program team with Dr. George Mensah at NHLBI. I have had the role of helping from the very beginning when we started this initiative in July, 2020, to think about, programmatically, what the initiative should be focused on, helping to develop its mission, its vision, and helping to craft the questions that we seek to answer, and think about the impact that we hope CEAL will have.

Barr: In your view, what has been the most exciting part of this endeavor?

Webb Hooper: CEAL has been very exhilarating, and I think that, probably, the most exhilarating part is understanding that it must move very quickly. CEAL was stood up even faster than RADx-UP and that is amazing in and of itself. We have witnessed from the beginning an infrastructure develop, really de

novo, so we now have 11 CEAL teams that are funded across 11 states. They are focused on addressing really important issues such as education about COVID-19, combating misinformation, addressing distrust, and working with community organizations and other stakeholders to have a positive impact, and encourage individuals to consider participating in COVID-19 clinical trials, vaccine trials, therapeutic trials, prevention trials, and also thinking about how we can ensure that the populations who are disproportionately affected are willing to accept the vaccines once they are eligible to receive them. Doing all of this in a very short time, maybe about a 90-day time period, has really been intense, it has also been exhilarating, and it has been just very rewarding to see the project come together. I think that CEAL is also important because it creates an infrastructure that has the potential to stand the test of time, that is to live long beyond, hopefully, our days when COVID is in the rearview mirror. We would like to see this refocus, if you will, on community engagement and community engaged research come back into the forefront of the things that we should be thinking about not only as we work with underserved populations, but as we think about how to address biomedical science problems and how we address medical conditions and their management in general.

Barr: What do you think, and this is may be a side issue, but what do you think are a lot of problems between communities and the science? In science, you know, medical: hospitals, doctors, institutions like NIH, the CDC, there sometimes seems to be a big disconnect.

Webb Hooper: Well, I think at times there can be and when you think about it, part of it depends on how we define communities. We know that there are pervasive health disparities that are observed among underserved populations in the United States, particularly those who have had a long history in the United States, and we also know from the literature and from the reported lived experiences over decades that the distrust that has been built up over time is because of situations that have happened, unfortunately. And what we are seeing is the collision of social issues that have been elevated in 2020, things that have been there and under the surface for a long time for many people, are now in the forefront. I think that there is a bit of a rift that we have to address openly and honestly. We have to seek to understand it, address it openly and honestly, and seek to understand what the strategies and approaches might be to really help to mend some of the major concerns that communities report. We must take it seriously if we want to see the health care systems and other large systems work well with communities. We have to demonstrate that we are serious about positive change work collaboratively to see change become a reality. I think that one of the silver linings, if you will, is that COVID has created is an opportunity in the areas of health care, public health, social determinants of health and health disparities, to look closely at our systems and how we have been operating. It is very complex, but I think we have an opportunity to try to address some of the problems that we have faced for many years.

Barr: Do you feel like with the CEAL initiative that you all are learning and taking in as much as you are trying to dispel misinformation and do education? Do you feel like it is the give and take or is it more one way than another?

Webb Hooper: The goal of CEAL is to be bi-directional and that is one of the primary principles of community engaged research. It has to be bi-directional. If the work is coming from one [group] of scientists telling communities what they should be doing or scientists thinking that we have the power,

ability, and the lack of humility to think that we can fix communities, then we're not likely to have the positive impact that we hope to have. CEAL is a very bi-directional initiative. The leadership of CEAL includes scientists, it includes community-based stakeholders, including faith-based stakeholders and others who have strong connections and have a large reach across the country with various communities. And we are intentional about ensuring that along the way we have the buy-in of all the stakeholders and the affected communities and that is, I think, one of the things that makes CEAL quite unique from other initiatives that are happening.

Barr: So today, what have been some obstacles that you have faced with this program? As well, has there been any surprise findings?

Webb Hooper: Obstacles is a good question, and I think thus far the obstacles have been trying to understand the misinformation and the sources of misinformation, the depth of disinformation, which is the deliberate spread of false information that makes it difficult to understand the choices and make informed decisions about the options that might be best for individuals or their families. We have addressed—we are working still to address—these concerns by developing tip sheets and resources. We have set up a fantastic website that is now in its third release. It is www.covid19community.nih.gov. We have gone through the landscape of needs to try to be as responsive as possible, recognizing that there are so many contextual and community nuances, and that is where we rely on the expertise of our CEAL research teams who are working on the ground with communities every day, and who understand that in different geographic locations and within different communities, customized resources may be needed. Those are some of the biggest challenges that we are still working to overcome.

Barr: Yeah. I had a chance to look at the site and it is quite impressive, so, that is really nice. I think we are going to move on to another way that you have been partaking in COVID activities and NIH, which is advocacy, which you do a lot of in your role as Deputy Director. So, in what ways have you shed light on health disparities related to COVID and advocated for changes to be made?

Webb Hooper: Well, when it comes to COVID-19 and really all the work that I am involved in, I approach it more from a science perspective rather than advocacy, although in many respects the data derived from science is to be used, and should be used, for advocacy purposes. One of the first things that we worked on was a commentary about racial/ethnic disparities in COVID-19 and we were fortunate that the commentary was published in the Journal of the American Medical Association (JAMA). In the commentary, we talked about the data that existed then. So, this commentary was published earlier in the pandemic in May 2020 and we talk about the disparities that were observed and, unfortunately, have persisted among African Americans, American Indians, Alaska Natives, and Pacific Islanders and Latinos, and we wrote about some of the reasons that underlie some of these health disparities. We also discuss the importance of recognizing and addressing the complex structural and social determinants of health, addressing racism and discrimination, addressing economic and educational disadvantages. We cover the importance of addressing health care access and equality. We also focus on the role of individual behavior as well. And so, that was one of the first things and that article has gone on to be cited many times and to be well utilized in the field. That is what we want – to inspire researchers to

really delve in on these topics to try to understand them and move us closer to being able to address them.

Barr: Yes. What are some concrete short-term and long-term solutions that you think that can be enacted to bring about some of the changes that we see are needed with COVID-19?

Webb Hooper: You asked a great question. I think about this from a multi-level perspective. Right, we need solutions that are at the individual level, at the interpersonal level, at the community or neighborhood level, at the health systems level, and at the policy level. These projects have focused, primarily, on solutions at the individual level and when you think about it from that approach, we need consistent and accurate messaging, we need systematic data collection that is also longitudinal so that we can report accurately on demographic and social determinants of health. Part of that depends on clinical systems so, you need systems level work because those are the entities that report to local and state public health departments and to the Centers for Disease Control and Prevention. We, also, I think, in the short term, need to focus on how we can ensure access to high quality care, how we can resolve testing deserts. You know, these are things that we have the ability to do something about, and I think on the positive side that since the pandemic started, when this was new and testing was scarce, that we have seen a major improvement in our infrastructure for COVID-19 testing. There are still areas that you would refer to as testing deserts, or geographic locations where test sites are not easily accessible, but I think we have made progress in that way, and as new technologies became available, such as the ability to complete home testing for COVID. There are ways, and it just means that there are solutions that are coming, that have happened, and we can expect in the short term.

Then, as we think about long-term solutions, we need more science that can result in improved understanding of COVID-19. It is a condition that we are still learning so much about every day, and this understanding from scientific studies may lead us to more targeted and effective community and healthcare system-based interventions, so we certainly need to move beyond the individual level to look at how the data that we are generating can guide intervention efforts, preventive health care, and how this information can be used to guide policy. I think that is where we are going. One important aspect of that, though, is making sure that the science does continue with this lens of community engaged intervention development, implementation and evaluation, and that is really what will help us lay the foundation for system-wide goals around decreasing health disparities.

Barr: Yes, that is really great. Have certain formats and channels worked better for you than others in discussing health disparities related to COVID-19? I know that you have done some writing, you have done some speaking, you have done some webinars, so have you found one has been better at reaching people than others?

Webb Hooper: Well, we are now in a virtual world and so, our formats and channels are much more limited than they were. Our options are essentially to write and to publish information and you can publish in multiple ways. You can publish, of course, in peer-reviewed journals, but you can also publish on blogs, you can share on social media channels, and other kinds of ways to send the messages out. In my in my experience thus far, I have felt that townhalls, webinars, and the opportunities to engage in Q&As, to have scientific discussions, and discussions with community organizations are great

ways to reach people. One that I found that was really great, [was with] one of my former partners. When I was in the in the academic setting, I delivered kind of a fireside chat with that organization, who focuses on addressing the needs of sexual and gender minorities and the unique concerns that these groups have with COVID-19. I found that experience and channel to be phenomenal and allowed for a more intimate in-depth discussion of some of the unique issues that communities are facing. Those are the kinds of activities that I find rewarding and I think help us all gain understanding and work through, in a collaborative way, some of the many challenges that we are all facing.

Barr: Yes. Can you speak a little bit about how your training and background has helped you with working with COVID-19? You are a clinical psychologist, you have worked with other health issues beyond COVID, so, you have a very broad perspective.

Webb Hooper: I do have a different perspective, and it is broad. I am a translational behavioral scientist, and I am a licensed clinical health psychologist, and I have dedicated my career and my life's work to the scientific study of minority health and racial/ethnic disparities. This work has focused on chronic illness prevention and health behavior change, and in my academic positions as a scientist, I led, for over 15 years, a community engaged research laboratory and we were focused on understanding multilevel factors and biopsychosocial mechanisms that underlie modifiable risk behaviors and the development of community responsive and culturally specific interventions. We also conducted community-based participatory research with a focus on distrust for healthcare and biomedical research in underserved populations. And joining NIH and having the opportunity to bring those perspectives and bring these areas of science into the project that we are working on, has presented a great opportunity to bring that kind of experience and knowledge to the forefront in these initiatives. It just happened, unfortunately, that this pandemic would occur with my starting at NIH, and the focus on health disparities becoming such a national conversation at this point. It is interesting how things work out, but my training lends itself very well to addressing health disparities in COVID-19.

Barr: Yeah, it definitely does. Well, in addition to these initiatives, what other COVID activities, just briefly, have you been involved with in your role, just to give people an idea of all the different things that you do?

Webb Hooper: I will just mention one activity. This, actually, was the first one that I started working on when I arrived and it is a COVID-related initiative that is called the social, behavioral, economic impact of COVID-19 in underserved and/or vulnerable populations. With that initiative we were able to develop funding opportunities that focused on interventions early on that were in the area of digital healthcare. We know that telemedicine has become instrumental to the delivery of health care in this context, particularly when things were shut down, and it was sort of the only way to see or communicate with a health professional. We also have a funding opportunity that has generated a really robust response, which is fantastic, and it is focused on community interventions to address COVID-19 in terms of the social, behavioral, and economic impacts, as we know that the pandemic has affected us in so many ways, such as mental health, and economics and social factors. I am proud of that work as well.

Barr: That is really great. We are going to transition from your role as a scientist to being a person living through this pandemic like every other American in 2020. One of my questions is: have you been working on campus at home or a combination, and what has the experience been like?

Webb Hooper: I was sworn in as Deputy Director on March 16, 2020, and it was a really memorable moment for me. About half of NIMHD staff had begun telework and they were able to watch my swearing-in on WebEx, versus what we anticipated, which was that we would all be in the room. I thought about this—and it was so exciting to join NIH—for months, and then this would happen on the day of the swearing-in, but it was still an amazing experience, and then, the very next day, the 17th, was the day that we went to 100% telework. So, I have been working remotely my entire time at NIH. I do work from home and the experience has been interesting. I think while some people would think that it is a really inopportune time to begin such a position, I don't see it that way. My learning curve has been steep and it has been intense, but it has been deeply meaningful work and I have been able to develop relationships that feel like relationships where I have met people face to face and I have only seen their faces on Zoom or WebEx. It will be so amazing when we can return to seeing each other and actually meeting each other in person, but I felt like everyone has been supportive. So it has been a great experience.

Barr: That is good. I can relate. I started on April 20th, so, I have also been remote the whole time. Definitely very different. What have been some personal challenges and opportunities for you that have arisen due to the pandemic?

Webb Hooper: There are challenges and opportunities. I think it is important to recognize that there are still some opportunities that have come about even with the pandemic. I think on the personal challenges side, I am a person who is very family oriented and my family lives in a different state. My closest family members live in South Florida and the biggest challenge is not being able to travel, not being able to see my family in person, has been really the biggest challenge. I also have small children who are in grade school, and the challenges of helping them make the transition to distance learning and make sure that they still have a great education. Those have probably been the two biggest of the personal challenges but there are opportunities and I think aside from the professional things that we have discussed; I have had the opportunity to really pause on some of the things I was working on, and some of the things I was doing, the constant hustle and the constant go, and really take a minute to sit back and just hold still for a second. Also, I really value spending time with my kids and so I have seen much more of them than I would have seen, with the typical working, driving, traffic, all of those things—I have seen so much of my children. It has just provided an opportunity for so much quality time with them that would just have never happened in any other circumstance.

Barr: That is very nice. Being remote and being part of NIH leadership, how have you gone about attending to the physical safety and emotional well-being of the staff who you help lead at your institute?

Webb Hooper: Yes. I mean, I think as a psychologist I am very concerned with the psychological and emotional well-being of everyone and including our staff at NIMHD, and some of the things that we have been focused on to make sure that we stay connected to the staff are we have monthly town hall

meetings, we also have staff meetings regularly, we also have informal check-ins. I check-in and have conversations with various staff just to make sure that they are doing okay. I also thought, going into the holidays, that NIMHD has a history of having an in-person holiday gathering, and I thought it was really important to make sure that even though we are remote that we think about how we can gather for the holiday. Other staff were thinking the same thing and making plans. So, last week, we had what I think was a great virtual holiday gathering that was interactive and engaging and even though it was in a virtual context, it was fun and enjoyable. Things like that, I think, are important to make sure that you stay connected.

Barr: Yes, definitely. This is a fun question. What is something about the holidays that will be different this year due to the pandemic for you?

Webb Hooper: That is fun question? I am kind of bummed I cannot see my family. Okay. But what is the positive?

Barr: I guess what are you most looking for, we can make this more fun. I guess that was a little depressing. What are you most looking forward to during the holidays this year? It has been a rough year for so many people.

Webb Hooper: It has. I enjoy the holiday season greatly and this year is definitely different, but I think we will enjoy. I will be cooking, I think, more than I usually would, and my children believe in Santa and they believe in the magic of Christmas and that's always fun for me to be able to help bring that magic to life for them. That is not different, but it is different in the sense that it will be my nucleus, like my five, the five of us, my husband and my three kids. It will be just an opportunity for us to have a Christmas, which we never have had, that is focused on us and our little family unit. We will make sure that we play lots of games, and we make it a magical, memorable experience for the kids.

Barr: Yes, definitely. Well, is there anything else that you would want to share as an NIH scientist or as a person living through the pandemic?

Webb Hooper: I think I have said a lot, but I just wish everyone, and I wish you the best. I am hopeful that we are going to come out on the other side of this and that we will, hopefully, be better in many ways as a result. I just hope that everyone stays safe and healthy and that we have a fantastic 2021.

Barr: I do, too, thank you very much for your words and I wish you and your family very happy holidays and all the best.