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ALEX MAIERSPERGER: How does where you live affect how long you'll live or how healthy you live? These are the questions research answers, and thank goodness for the skill set of researchers. They've given us answers to some of society's most pressing questions.

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I'm your host, Alex Maiersperger. And today on the Health Pulse podcast, we're joined by two of the best researchers, Dr. Joyonna Gamble-George, neuroscientist at Yale School of Public Health, and Dr. Karriem Watson, chief engagement officer of National Institutes of Health All of Us Research Program. Welcome, Dr. Gamble-George and Dr. Watson.

JOYONNA GAMBLE-GEORGE: Thank you.

KARRIEM WATSON: Thank you.

ALEX MAIERSPERGER: Both of you are now involved with National Institutes of Health All of Us Research Program. But before you got there, can you tell us a little bit about what drew you into the research world? Dr. Gamble-George, would you go first?

JOYONNA GAMBLE-GEORGE: Yes. So growing up on a farm in rural Alabama really opened my eyes to the stark health disparities right in my own backyard. I watched as my grandparents and neighbors had to travel over an hour just to see a doctor. These experiences shaped my resolve to pursue a PhD in neuroscience and just delve deeper into the root causes of health disparities.

After earning my PhD from Vanderbilt University, I then joined the National Institutes of Health National Heart, Lung, and Blood Institute, also known as NHLBI, where I worked in the Center for Translation Research and Implementation Science. After my tenure at NIH, I then became involved with the All of Us Biomedical Researcher Scholars Program at Baylor College of Medicine. And one of my key projects from this program involved studying the genetic and environmental factors contributing to heart failure in African American women with lupus. This research, conducted through the All of Us Researcher Workbench, aims to uncover tailored interventions that could improve patient outcomes.

This research then led to another pilot project, where I am currently using SAS software to analyze the prevalence of negative social determinants of health among adults who have experienced life-threatening medical events or chronic diseases. This project stemmed from my own personal experience when my mother suffered a stroke and dirt-poor-quality health care services after being admitted to a hospital. Her experiences impacted her trust in medical providers and her use of health care services. So I just wondered, if this happened to her, how many other people in the US could this have happened to as well?

So as a result, the study I'm currently conducting seeks to understand how negative social determinants of health, such as poverty and lack of education or access to health care, correlate with mood impairments, substance misuse, and health care use, which is really important for designing more effective health policies and interventions targeted at these populations. All of these experiences, from my childhood on that farm to even my current research projects, have shaped my journey into the world of health science and research. It drives my commitment to addressing the health inequities that affect the most vulnerable populations, especially within the US.

ALEX MAIERSPERGER: Love it. Feels like a great give-back story of you took your family's experiences, your personal experiences, and were able to take your education to levels where you can give back to others. Dr. Watson, what pulled you into the research world?

KARRIEM WATSON: Thank you so much for that question, Alex. I'm humbled by Dr. Gamble-George and I, the overlap in our stories and our lived experiences. And I'm also sparked by the recurring message of the importance of programming for youth, the importance of letting youth know that there's ways to engage them in science. What first got me involved in science was actually my lived experience.

Similar to Dr. Gamble-George, my family is from the rural South. My dad was from rural Arkansas. My mother was from rural Mississippi. And like many African American families in the '60s that they moved up north for better opportunities, and that led them to a Midwest town in Michigan. And they settled in that town and raised a family, only for, later on, my birth mother to find out that she had breast cancer. And I was seven years old when my birth mother was diagnosed with breast cancer, six or seven.

And at the time, because we lived in a small town in the Midwest, although it was not rural, it had access issues very similar to rural communities. And we did not have access to an academic medical center. And although I didn't know those big languages back then as a child, I just knew that my mother was dying and wasn't getting the help that she needed. And after a double mastectomy and treatment and several bouts of treatments that were not as effective as the ones we have now, my mother, unfortunately, passed away from complications of breast cancer in the early '80s.

And this was before drug development was what it is today. And there was definitely no precision medicine out there, at least not in my hometown. And then fast-forward, my dad gets remarried, and now I have a new mother. We did not use the word stepmother in our home. I grew up in the traditional African American church, and my dad was a deacon in the church. And so our family core was very important. And my dad remarried 2 and 1/2 years later, and then my new mom gets breast cancer as well. But because of my dad's understanding of improved health literacy, although that's not the terms he used-- he would not have to say it that he had increased health literacy. And he also would not have described himself as a patient navigator. But that's what happened. He had increased health literacy, what he had learned from my birth mother's experience, and he knew how to navigate his new wife through the system. He even advocated for her to get care in a place where he had heard of other friends and colleagues getting care.

And as a result of that experience, my new mom went on to live a long and healthy life until she was diagnosed with lung cancer right during the pandemic-- right before the pandemic in 2020. And that was really tough for me because here I am now, a cancer disparities researcher, doing research in community-based participatory research. A lot of my family experiences led me to understand and have a passion for science. And my own mother is being impacted by lung cancer, and there was nothing I felt I could do about it.

But there was something I could do. I made a call. And I said, before you start my mother's chemotherapy treatment, can we make sure-- can we do molecular targeted testing of her tumor, because there's some new innovative drugs that are out that are a result of new clinical trials that have just-- the new FDA-approved drugs. There's innovative treatment. But where she was getting her care, they didn't know necessarily about clinical trials. They knew, but that's not one of the first things that was offered.

And lo and behold, my new mom did-- she did qualify for molecular targeted therapy and went on to have a year of better quality of life. She did end up passing away from complications of end-stage lung cancer. But her quality of life was amazing during that year. And while medicine and innovation didn't extend the quantity of her life, it did extend the quality of her life. And when I think back and look over my life, what got me involved in science, it's those lived experiences, being affected by it firsthand.

And I started off in clinical trials, in traditional clinical trials, where I was a clinical research coordinator. And like Dr. Gamble-George, I wanted to be more of the person deciding how these drugs are developed and innovated. And I remember learning about inclusion-exclusion criteria, which are criteria that allow some people to enroll in the study and some people not to enroll in the study.

And at the time, I was working on diabetes medication, a new diabetes medication. And populations with the greatest burden of disease, minoritized populations like African American and Hispanic and Latino, were not being enrolled in this study, in large part because-- not because they did not want to participate, but because of, A, where the studies were being conducted in your big academic medical centers. B, no one was asking them. And then when they were asked to be enrolled, they wouldn't meet the criteria because the studies weren't designed in a way that were inclusive to address the needs of larger populations.

So I knew I wanted to be on the other end of that. I wanted to be the one designing the studies. So I went back to school, and I got into contact with an amazing advisor, Dr. Robert Wynn, who became my postdoc advisor. And under Dr. Wynn's leadership, I learned how to design clinical trials. I learned how to develop cancer prevention and control studies and precision medicine. I learned how to bring the community into the work that we were doing, give the community a voice that informed the research that we were doing.

And I learned that when you do that, you debunk these myths that African Americans and other populations don't want to participate in clinical trials. I also debunked the myth that there was this-- that African Americans are a hard-to-reach population. I hate that term because I don't think any population is hard to reach. I think they're under-engaged. And these are all things that I learned throughout my postdoc that I end up carrying into my career as an NIH, NCI-funded, NIMHD-funded researcher addressing cancer disparities in high-risk populations.

ALEX MAIERSPERGER: What an honor you've brought to both of your mothers' legacies, and what a blessing you are to other families that will have longer lives or better quality of lives because of the research that you've done. You also mentioned under-engagement. And now as having engagement in your title, as chief engagement officer, can you help us understand a little bit more about this All of Us initiative, maybe your role in it? Who and how can people participate? And maybe most importantly, what is the thing that you're looking to find out with this research?

KARRIEM WATSON: It's a great question, Alex. The All of Us Research Program sponsored by the National Institutes of Health, the NIH, is the NIH's largest precision medicine initiative. We're rooted in the-- in 2016 came out of the idea that trying to move away from a "one size fits all" approach to medicine. When people ask me, what is precision medicine, I often tell them, precision medicine is moving away from thinking that everyone operates the same way. Our bodies are all different. Even our exposures are different. And you started at the top of the hour saying even your zip code can have just as much impact on your health outcome as your genetic code, your DNA.

The All of Us Research Program is an innovative research program by the NIH setting out to collect data from a million or more people over a period of time and to make that data readily available to researchers. Unlike some research programs or research questions or projects that are trying to see if new drug A is better than new drug B or if this intervention is better than that intervention, All of Us is a little different. We're collecting data and different types of data types so that we can collect data and understand DNA, genetic history, electronic health record data, even survey data. We ask questions about where you live, what you eat, and your experiences with the social determinants of health.

All this data is collected through the All of Us Research Program. And then our other objective is to make that data readily available to researchers like Dr. Gamble-George, where they can interrogate that data and ask questions about that data and develop research questions from that data so that we can really better understand how individuals are impacted by certain things.

Recently, we hit a milestone, Alex. We just recently returned data to 100,000 participants on their medicine and how that interacts with their DNA, called Medicine and Their DNA, and also on genetic information about any mutations we may have. As a participant in the program, when I got that data returned back to me talking about certain medications that I may metabolize differently based on my DNA, based on my ancestry, that was a game changer for me. And it's a game changer for the hundreds of thousands of people who have received that information back. That's what precision medicine is, and that's what the All of US Research Program is setting out to do.

ALEX MAIERSPERGER: I'm going to take a moment just to clap here of the undertaking and the initiative. Dr. Gamble-George, there's often significant societal mistrust in research. It brings to mind tobacco companies paying for studies that said smoking was good for you. And so there's some of that societal feeling. What are some of the ways research has improved, and what's happening now in research that's going to make it even stronger in the future?

JOYONNA GAMBLE-GEORGE: So there's a long history of skepticism towards research, often fueled by incidents like tobacco companies funding studies that falsely promoted smoking as beneficial. It's really important to acknowledge these issues. But it's also equally important to recognize the significant strides we've made to enhance the trustworthiness and effectiveness of research. We've improved the peer review process, making it more rigorous and transparent. Nowadays, many academic journals will use either double-blind or open peer review methods to minimize bias, either hiding the identities of both the reviewers and the author or disclosing both.

Additionally, the push for open data is transforming the landscape. Researchers are increasingly expected to make their data sets publicly available, which bolsters the reproducibility of research. But it also facilitates independent verification of a study's results. Also, the registration of clinical trials and study protocols and publicly accessible databases before the research even begins has become a standard requirement. This practice counters selective reporting and ensures that all research is documented, irrespective of whether the outcomes are positive or negative.

ALEX MAIERSPERGER: It sounds like a broad swath of things are improving research, from the diversity and collaboration, access. Dr. Watson, are you seeing the same things?

KARRIEM WATSON: Definitely seeing the same things and so happy that Dr. Gamble-George talked about access. That's one of the bedrocks of our program and our key values is to make the data pool in the All of Us Researcher Workbench available to researchers who can really get at asking those questions. And we reached another landmark benchmark in our program, where over 10,000 researchers are now registered to utilize our data. That's a game changer.

And it's also exciting that these researchers, these 10,000 researchers, they also reflect the diversity of the US, from being from institutions in rural areas, from being from institutions that are minority-serving institutions, historically Black colleges and universities, even Hispanic-serving institutions. All these researchers from diverse backgrounds and diverse places with diverse skill sets are part of that 10,000. And so the more we can have access of diverse researchers utilizing this data with different skill set, that gets at that team science that Dr. Gamble-George talked about.

I was fortunate enough as a researcher to address lung cancer screening on the South Side of Chicago. And in that research project-- you talked about community engagement is in my title. It's in my blood. I've been doing community engagement my entire life. My dad was a community organizer. So I brought his background in community organizing and combined that with the science, and that's the type of work that I do.

So when we had this model of citizen scientists where we engaged African American men, we had barbers. We had pastors. We had fraternity members and community leaders who were in the community and had an amazing reputation in the community. We brought those men into our Cancer Center and trained them over several Saturdays as citizen scientists. These men even got trained in the Institutional Review Board process, the IRB process that Dr. Gamble-George talked about. And then we sent these men back out into the community to engage their communities and their networks with us. We had hundreds of men coming to faith-based institutions, talking to their barbers about prostate cancer screening and debunking a lot of those myths.

And as a result of that community engagement and that citizen scientist work, we then had those same men now working on a lung cancer screening project with us. And where team science was important was our project was looking at lung cancer across basic science, population health science, and even environmental exposures. We had a basic scientist looking at protein methylation. What's happening at the cellular level? When certain populations smoke, no matter if they smoke a little or a lot, they may react differently. That's at the cellular level protein methylation.

Then we had another scientist looking at the population level saying, does where you live, your zip code, matter? Are there environmental exposures that you're experiencing? Based on your zip code and your life experiences, are you under an elevated amount of stress? So those barbers that were involved, they were collecting hair samples. From those hair samples, we were looking at cortisol levels to look at stress levels. And then you had me, the community-engaged scientist, bringing all of that together. That's an example of team science.

Now, where does the All of Us Research Program data set fit in with that? It took us a long time to get a lot of that pilot data. We had to go through a lot of different data sets, a lot of different EHRs finding a lot of different places. And it took a long time to get a sample size and what we call in science powered enough in order to be able to do this work.

I did a little exercise where we looked at All of Us Research Program. And I said, what if I had access to the All of Us Research Program data set? Would I have been able to answer some of that pilot data questions sooner and more efficiently? And Alex, the answer was yes. I was surprised and amazed at the amazing amount of data we had. And over 155,000 of our participants had identified that they had smoked over a hundred cigarettes in their lifetime. That's amazing data.

We even had data on people who had smoked cigarillos and electronic cigarettes and other things. And I was like, this is a wealth of data that I wish I would have had when I was a trainee and a researcher. So I'm so excited about now engaging communities and what that means to say, yes, you should be involved in all aspects of this, from those collecting the data to those analyzing the data.

ALEX MAIERSPERGER: Really incredible to hear about the advances on the people side, engagement side and the technology side. The word cutting-edge and groundbreaking can be used in research. And now that there's incredible amounts of data and maybe new types of data and newer technologies, like you mentioned AI, how are you seeing these contributing to your roles and your studies?

JOYONNA GAMBLE-GEORGE: So in my work, it's clear that cutting-edge technology and research methods are reshaping how we collaborate and expand our understanding to complex health issues. With the emergence of big data, we're now able to process and analyze vast amounts of information, from genetic to environmental data, using AI algorithms and even machine learning. These tools are indispensable for drawing insights that would be practically impossible to manage manually.

AI is particularly transformative in its ability to identify patterns and predict outcomes within these complex data sets. This capability is really important in fields like epidemiology, where predicting future trends can greatly enhance decision-making and policy development. Also, AI is streamlining research by automating routine tasks, such as data entry and literature reviews, which helps to boost efficiency. And it reduces the likelihood of human error. So this frees up my time as a researcher and that of my colleagues to tackle more complex challenges.

Also, AI-driven simulations and modeling are revolutionizing fields from pharmacology all the way to environmental science, allowing us to test hypotheses and visualize outcomes from our research without the need for expensive physical experiments. This not only saves time but also resources. And it, as well, accelerates the pace of scientific discovery.

ALEX MAIERSPERGER: Dr. Watson, how is technology shaping up your world?

KARRIEM WATSON: Technology is shaping up my world by-- we're actually working very hard in the All of Us Research Program to minimize what we call the digital divide. We understand that our program is a very tech-heavy program. We understand that in order to get access to our data, you have to learn a lot-- know a lot of coding languages. We also know that in order to get access to our data, you need things as the internet and access to broadband. And we saw during the pandemic that that access is not as widespread as we always think that it is.

And so one of the things we do is acknowledge that to make sure that we work with organizations like the National Library of Medicine, for example, that works with several libraries to ensure that people who may have internet access or lack of access to computers or iPads or other instruments can get that through their library if we have a partnership through the NLM, the National Library of Medicine. We also partner with Baylor College of Medicine and Xavier University and others to do data training.

One of our community engagement partners is DREF, which stands for the Delta Research Education Foundation. DREF is a not-for-profit arm of the second oldest African American sorority in the country. People may hear sororities and fraternities. You may think college life. But actually, in the African American community, sororities and fraternities are actually civic organizations that have reached far beyond the college campus life. They actually are amazing leaders in the community with trusted partners. So by us partnering with DREF, that actually allows us to get trust by proxy in several communities.

But one of the other amazing things that it does is that DREF has what's called DREF 22, which are 22 African American women scientists who are utilizing All of Us data, asking questions that are important to the African American community around high blood pressure and the impact of fibroid tumors in maternal and child health and the role of stress and you name it. And so as a result of those partners like DREF, Baylor College of Medicine, and even PRIDEnet that host boot camps where scientists that are addressing research disparities and sexual and gender minority communities can come together and learn how to use the All of Us data set.

And even lastly, we partnered with another community-based organization called CCPH, Community Campus Partnership for Health, that is working with RTI to do roadshows of the data to HBCUs. Just today, I was on a call earlier with Norfolk State University talking to faculty there. Earlier this week, I was on a call with the Community College of Mississippi as well as Jackson State University on this data roadshow.

So what is the All of Us Research Program doing to democratize the data? We are taking the data to the community. We are doing that in a way that is innovative, in a way that minimizes and mitigates those barriers of access that we often see, and also building capacity. The fact that 1 in 3 historically Black colleges and universities, HBCUs, have a data use research agreement on our Workbench is a testament to the innovative ways that we're trying to do that community outreach and engagement.

And last thing I'll say, Alex, about this is that I was so proud that recently we had our first tribal college university sign up and get an MOU with our organization to talk about, how can we ensure tribal sovereignty and engaging American Indian and Alaska Native communities in our program? Alex, that's why when you said you wanted to join, I want you and others to go to joinallofus.org to think about how can your data become a part of our program by going to joinallofus.org.

ALEX MAIERSPERGER: I'm fired up about joining. I'm fired up about research. I'm so excited to hear the ways both of you honor your families' legacies and are finding answers that are going to lead us to a healthier future. Dr. Gamble-George and Dr. Watson, thank you so much for joining us today.

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For our viewers and listeners, we know you have infinite ways to spend your time. Thank you for choosing to spend a little bit of it with us. If you'd like to join as a guest or if you'd like to leave a comment, please email us, thehealthpulsepodcast@sas.com. We're rooting for you always.