

SCOTT WRIGHT: Good day. I'm Dr. Scott Wright from Mayo Clinic, a professor. And today, I have the privilege of convening a roundtable review on the perceptions and attitudes toward health-related research participation among African-American women. I'm joined today by my colleagues, Dr. Sharonne Hayes, founding director of the Women's Heart Clinic at Mayo Clinic and now director of diversity and a longtime researcher in this field, and Dr. LaPrincess Brewer, one of our advanced clinical fellows, who has also graduate work in this topic. Welcome.

LAPRINCESS BREWER: Thank you.

SHARONNE HAYES: Thanks for having us.

SCOTT WRIGHT: Thank you, both, for coming. Thank you. It's a great topic. We are here to discuss what I have described as an absolutely brilliant survey and paper led by our two discussants, Dr. Brewer and Dr. Hayes, about the perceptions among African-American women and their participation in clinical research.

Let me start by saying to both of you, well done. What a fantastic paper and research project. I know it took several years, Sharonne, but it is outstanding. Congratulations.

SHARONNE HAYES: Thank you.

SCOTT WRIGHT: The paper's entitled "The Perception of African-American Women and Their Attitudes Regarding Research Participation in Medical Research," the Mayo Clinic and The Links, Incorporated Partnership published in the *Journal of Women's Health*, volume 23, November 8, this year, 2014. It was designed by a team led by Dr. Hayes. And, Sharonne, let me commend you on this, and just describe for us for a moment, if you will, the background for this and how you got connected with The Links and what a great opportunity it's been.

SHARONNE HAYES: Well, as many things that happen at Mayo Clinic, often it is patient-driven. So it actually was a very grateful patient, who was a Links member who really wanted Mayo to work with The Links, Incorporated to advance both of our missions, particularly among health disparities. And we worked with Dr. Monica Parker, who is a family practitioner and was their national chair of Health and Human Services. She's at Emory University.

So we had discussed mutual priorities and decided that this was an important one. And as Dr. Parker had indicated, she said, you know, there is no research about people like me-- educated individuals who maybe were just not asked. And we think that we need to be part of the solution for African-American health. So it was through her mentorship and leadership and the collaboration that we came up with a way to use the resources at Mayo Clinic to develop the survey and have The Links as the perfect survey participants.

SCOTT WRIGHT: Now, the survey participants are, by any measure, a group of leaders who are empowered. I mean, 95% are either actively working or retired as professionals. 95%, I think, had college degrees. Over half of them earn more than \$150,000 a year-- maybe a third to a half, very successful women leaders.

What was it like to sit in the room with these powerful people? I mean, you can describe them. But I imagine, they were leaders in every community in this country.

SHARONNE HAYES: So The Links, Incorporated is a national organization. And it is the leaders in these women's communities. So they are doctors, lawyers, judges, business owners.

And it was very clear in having conversations that they wanted to make a difference in their communities. The Links, Incorporated isn't just something where somebody donates money, and then they're done with it. They actually have a required number of volunteer hours every year or they're out if they don't do it.

SCOTT WRIGHT:

SHARONNE HAYES: So this is a group of women who want to make a difference. This aspect of Health and Human Services and health disparities was a relatively new focus for the organization. So it did really allow us to leverage the talents and the enthusiasm of that group to work together.

SCOTT WRIGHT: Amazing. Well, Dr. Brewer, could you summarize briefly for us the findings of this initial paper.

LAPRINCESS BREWER: Great. Yeah, so we sought to evaluate their perceptions and attitudes towards medical research amongst the African-American women of The Links, Incorporated, which is an international service organization. And we thought that this group would bring a unique perspective than those that have been traditionally studied in lower socioeconomic groups. And we surveyed them on their willingness to participate and the intention to participate in medical research and also obtained their attitudes in general towards research.

And we had great results. So we found that they were really willing to participate in a variety of research studies, particularly those involving interviews and those with their provision of blood samples. And their attitudes towards research were overall positive. They felt-- the majority felt that participation in research was beneficial to society. It would mean better care to them and others in the community at large, and that it would help to reduce health disparities.

SCOTT WRIGHT: Historically, this has been a community of research participants, where it's been a little challenging to see an enthusiast participation, right? I mean, historically, we have the unfortunate Tuskegee experiment that took advantage of a group of African-American men, as I recall.

And then there's been perceptions within this community, or within, let's say, minority communities in general about what does this mean? Will I be treated fairly? Will I get the best care? Were any of the findings surprising to you, Sharonne, in terms of the historical nature of this? And do you still see us as having a significant amount of distance to cover to improve research opportunities for non-majority groups?

SHARONNE HAYES: Well, I think what was heartening was that, among this group, who are leaders and thought leaders in their communities, there was a much greater acceptance of being a part of research. And so we looked at that as an opportunity, that we might use the links in their communities to help move things.

On the other hand, there still was a fairly high level of concern about-- for instance, I think what surprised us a bit was the use of their medical record. I think a lot of us who work at Mayo, where a lot of our work and our reputation has to do with looking at past medical records and saying, the 100 cases of whatever, that this was-- And so we can only conjecture, but maybe it is a sense of mistrust and privacy.

And I think it is the mistrust because of most health care organizations and researchers being people who are in a big building that's far away and for people who don't look and act like our participants, that we still have a lot of things that we need to do as a research organization to be in those communities, because that's really the only way we'll build that trust.

SCOTT WRIGHT: Indeed, indeed. I think, 21% of the survey respondents said they thought it might be unsafe to participate in clinical research. Now, these respondents are the most upwardly mobile, empowered-- economically empowered and socially empowered members of any community-- majority or minority. And yet, a fifth of them are concerned.

And yet, they're very well-educated, highly intelligent, highly successful. What insights did you glean from that in terms of that? That number struck me as a little high. I would've expected it to be lower. But I accept it for what it is.

SHARONNE HAYES: Well, and we didn't have a reference group. So I'm not sure if we asked a general population that very question. Because when you think of research, sometimes people talk about being a guinea pig. And if you have an end-stage heart problem or cancer problem, you are often much more willing to participate and take that risk.

We were asking a predominately healthy population. And so for them, maybe in their mindset thought, well, if I were to do-- I'm feeling well now, if I did it. So I don't know what to make of it. But I think it's something-- what it tells us, we need to address that up front in our consents, in our conversations with all research participants to weigh the risks and the benefits.

SCOTT WRIGHT: And to maybe reassure them that they lose no option for health care by just being in research.

SHARONNE HAYES: That's right.

SCOTT WRIGHT: Dr. Brewer, what lessons do you see here from individual researchers, like you and Dr. Hayes and me, talking with patients and trying to recruit more minority subjects? What lessons can we learn from a researcher standpoint? Then, Dr. Hayes, I'm going to ask you if you could talk about it for more of a organizational and a big picture standpoint.

LAPRINCESS BREWER: So I agree that, in order to increase the diversity of our research pool, we must go out into our communities and educate them on the benefits of research participation and also let them know how we plan on using data from clinical trials to their direct benefit and towards the eradication of health disparities. And I think it's also very important that we move from a kind of us versus them to a we paradigm, towards redefining our research priorities. And I think this can definitely assist us in developing more of a partnership amongst medical institutions in our communities.

SCOTT WRIGHT: Thank you.

SHARONNE HAYES: Well, I think I'll build on that, because I think our community based, participatory research initiatives that we're doing here at Mayo and across the US, other organizations, where it is-- we're going into the communities, talking, meeting in their, whether it's their place of worship or at The Links national convention, that says, we're partners. And that is the best way-- I mean, just like being invited to a friend's home-- there is a different comfort level than going to seeing them at work.

So I think we need to up our game on that. And from an institutional standpoint, we need to train our colleagues to be comfortable and embrace it, because it's a very different paradigm than what we've been traditionally taught about research. And I think, wearing my diversity and inclusion hat, I think increasing the diversity of our staff and our researchers is critical.

And if we don't have individuals who are researchers of that community for which we're trying to reach out, then using novel methods by hiring community liaisons who can help us as researchers understand the cultural needs and the research needs and the communication needs of those communities. Now, those are all things that we're doing at Mayo more frequently. And I do think that's going to reap a lot of benefits for us.

SCOTT WRIGHT: Well, as I understand it, the two of you are involved in a couple of innovative research projects at the moment-- one looking at houses of worship and one doing remote-based cardiac rehab care to address these issues. Would either of you care to comment on that and just describe for the people watching today what you're doing to give them some ideas on what innovations they might bring to their practices?

LAPRINCESS BREWER: So as a part of my passion, I really would like to increase awareness of health disparities, not only amongst the population that I plan to study, but also amongst my colleagues in medicine. And through my research through community based, participatory research in local African-American churches, I plan to increase knowledge and awareness of heart disease, so that I can then, in turn, help to eradicate this in a population that needs the most help as possible.

And currently, we are working with local African-American churches here in Rochester, Minnesota, with a prevention program in which we bring in experts from Mayo Clinic to teach our participants on heart disease risk factors.

SCOTT WRIGHT: How is it being received?

LAPRINCESS BREWER: It's going very well, actually. They're really excited to see our faces. They're really eager to learn. And they're excited about the long term partnerships that can come out of our research.

SCOTT WRIGHT: This is marvelous. So researchers should not be afraid of being creative and going into the community, should they?

LAPRINCESS BREWER: Not at all.

SCOTT WRIGHT: Sharonne, do you think we could improve health care delivery doing the same models?

SHARONNE HAYES: I think this is the only way that we will improve health care delivery, because if we aren't including all of our populations that are under our care and don't understand their cultural and educational needs and their health needs, then we won't. Another thing that came out of this project and this partnership with The Links, Incorporated, it's ongoing.

So the senior author on this paper, Dr. Carmen Radecki Breitkopf, is a co-PI with the Links scientists at University of Michigan. And we've received NIH funding to take this initiative, work with the Links chapters to develop educational programs, both for Links members, these influential women, but for them to then take into their communities to increase awareness about the need for full participation by all communities, because through that full participation will be better health.

SCOTT WRIGHT: And if we have people watching today from large academic research organizations or sponsors, drug companies or others, and they're interested in partnering with you and Mayo and The Links, would it be OK if they contacted you?

SHARONNE HAYES: I would welcome that.

SCOTT WRIGHT: I think it's a splendid idea. As I've shared with both of the doctors with me today, I spent the last seven years working on some large clinical trials. And we identified that especially minority women were among the highest who discontinued study drugs.

And we feel strongly, as trialists, that unless the trials can be generalized to all populations, the data is less than perfect. And yet, we struggle with trying to figure out how best to retain these subjects. What advice do you have for trialists watching today about how they can better keep subjects who are less affluent or who are in minority populations in trials?

SHARONNE HAYES: Well, I think being creative and understanding. So it is through research like this that will better inform and help our research colleagues. But if you are recruiting for a trial and you are not getting enough of any type of subject, so that you're going to have meaningful data, I think that then really targeting-- and I think bringing in somebody who is interested in those communities.

We have folks here in Rochester that are specifically working with Somali communities on GI diseases that specifically affect Africans. And you can't just walk in and say, I'm going to-- I'd like to study a liver disease on you today-- so having those community connections. And I guess that's probably the best. And perhaps exit interviews on individuals that do decide to drop out of a trial and understand what it was-- is it child care, is it parking, is it something that--

SCOTT WRIGHT: Of course.

SHARONNE HAYES: Is it being a caregiver for someone at home and being unable, especially for women.

SCOTT And also recognizing that perceptions and attitudes about distrust and historical issues and being sensitive to
WRIGHT: that. Well, congratulations, again, to both of you and all of your colleagues on the paper. It's a tremendous initial publication. I look forward to more research. And, Dr. Brewer, I hope that you'll continue this passion in your entire career in doing this, because you're off to a great start. And I want to thank you for your commitment to doing this.

LAPRINCESS Thank you.

BREWER:

SCOTT Well, I want to thank our two guests today, Dr. LaPrincess Brewer and Dr. Sharonne Hayes, and congratulate
WRIGHT: their entire research team for the efforts today. I want to thank you for joining us.

And I want to challenge each of you, who are watching, to consider what you can do to engage more underrepresented populations to participate in clinical research, so that the data we discover can be taken to all populations and help all people. Thanks again. This is Dr. Scott Wright from the Mayo Clinic Division of Cardiology. We're glad you joined us today.