Minorities, especially African-American women, remain vastly underrepresented in clinical research studies, even though the National Institutes of Health (NIH) Revitalization Act of 1993 stipulates that scientists receiving NIH funding must explain in their proposals how they plan to enroll more minorities and women in their studies.

Disparities in care that result from too few women being included in such studies has been a source of frustration since the early 1990s for Sharonne Hayes, MD, a Mayo Clinic cardiovascular disease specialist who founded the Women’s Heart Clinic and is now medical director of diversity and inclusion at Mayo.

“When I had a man in my office who was recovering from a heart attack, I had far more definitive answers based on scientific evidence than I did for the women who were sitting in my office because prior research had often excluded women,” she says. “Those disparities doubly disadvantage African-American and Hispanic women because even if they have access to a health care provider, that provider does not have the evidence available to them to give them the best care.”

When Hayes and her colleagues decided to find out why fewer African-American women participate in medical research studies, they got help from one of their patients, who is a member of The Links, Incorporated, a national service organization for African-American professional women.

Working with a medical researcher from Emory University who also is a member of The Links, the Mayo team asked members of the organization to complete an anonymous survey while attending their 2012 National Assembly in Orlando. The survey evaluated their thoughts about medical research by having them indicate their level of agreement with several statements (for example, “Participation in research will mean better care” and “Scientists cannot be trusted”).

The participants also were asked how willing they are to participate in clinical trials, interview studies, biobanks, genetic research, medical records reviews and studies that require providing biological samples. Findings from the study were reported in the *Journal of Women’s Health* in August 2014.

Says LaPrincess Brewer, MD, MPH, an advanced cardiovascular disease fellow at Mayo and a co-author of the article: “A lot of what we understand about African-American participation in research comes from more underserved communities, people who are in a lower socioeconomic status. No one had taken a look at the

“The biggest barrier to participation is that the women simply were not being asked.”

– Sharonne Hayes, MD
Cultivating diverse researchers

Studies have shown that when controlling for all variables, biomedical researchers from underrepresented racial and ethnic backgrounds are not funded by the National Institutes of Health (NIH) at the same rate as their white counterparts. The University of Minnesota is trying to close that gap with the help of a $22.4 million NIH grant it is sharing with four other institutions: the University of Wisconsin-Madison, the University of North Texas Health Sciences Center, Morehouse School of Medicine and Boston College.

“The hope is to change the face of science through mentorship, networking and professional development,” says Kristin Eide, MPH, assistant director of professional development for the University of Minnesota’s Program in Health Disparities.

The university is using its share of the grant dollars to coach less-experienced researchers in biomedical and federal grant writing. Participants interested in the program will prepare a grant application for a research project that will ultimately be submitted for review. Eide says they will collect data on whether the trainees’ projects get funded.

“The model is unique,” she says. “Rather than just listening to presentations, trainees go through a process that helps them understand the way an NIH reviewer thinks and what problems might stand out that might ultimately lead to their not getting funded.”—J.M.

highly educated, upper echelon of the African-American community.”

Willing—but wary

The findings supported the investigators’ hypothesis: That the desire to participate in medical research was much higher among The Links members than among previously studied African-American women of lower socioeconomic status. “Many of The Links members had not participated in medical research, but the vast majority were willing to participate and believed that participation would be good for the African-American community,” Hayes says. “The biggest barrier to participation is that the women simply were not being asked.”

What surprised the team is the fact that these educated, informed women still had concerns about the ethics surrounding research participation. “They were actually more willing to give blood and tissue samples to a biobank than to allow a researcher to review their medical chart,” Brewer says. “It shows us that we as researchers need to be more up-front and transparent about letting them know what we are doing with the data, and that the data not only are protected but also are beneficial to the public.”

Many of the women surveyed said participating in research felt scary or made them feel vulnerable. But they also realized that the benefits outweighed these concerns. “The sense we got from participants,” Hayes says, “was, ‘Yes, I have reservations, and I have more reservations than the average 50-year-old white man. But I also understand that if I don’t participate, there won’t be anyone who knows about people like me.’”

Publishing the study’s findings was just the beginning. To get at some of the reasons for the women’s answers, the team received an NIH grant in the spring of 2015 to conduct focus groups with members of Upper Midwest chapters of The Links.

Led by Carmen Radecki Breitkopf, PhD, from Mayo, the research team will use information from the focus groups to work with members of The Links to develop an educational program about research participation for African-American women.

Hayes believes there are key takeaways from the survey that clinical researchers can act on immediately. “Ask African-American women to participate in your research,” she says. “We need to stop assuming that they’re not willing to participate. We still may have a lot of people who will say ‘no,’ but if they are never even asked, they certainly won’t participate.” MM

Jeanne Mettner is a Minneapolis writer and frequent contributor to Minnesota Medicine.