Colleen McBride, PhD

Colleen McBride, PhD, is a senior investigator and chief of the newly formed Social and Behavioral Research Branch (SBRB) of the National Human Genome Research Institute (NHGRI) at the National Institutes of Health. The SBRB is an intramural research program with the mission of conducting a broad spectrum of research to understand how to best apply genomic discoveries to improve health and well-being. Before coming to NHGRI, Dr. McBride spent 8 years leading Duke University's Cancer Prevention, Detection and Control Research Program. Dr. McBride is a behavioral epidemiologist and is nationally recognized for her research in the development and evaluation of self-directed behavior change interventions. She has developed and evaluated large randomized trials; a number of proactively delivered behavior change interventions for smoking, diet, and physical activity; and motivational adjuncts, including genetic susceptibility testing.

Dr. McBride received her doctorate in behavioral epidemiology from the University of Minnesota in 1990.

JIM: Prior to becoming head of the Division of Intramural Research (DIR) within the newly created Social and Behavioral Research Branch (SBRB) of the National Human Genome Research Institute (NHGRI), you were a prominent behavioral epidemiologist and director of the Cancer Prevention, Detection and Control Research Program at Duke University. What led you to a career in social and behavioral research? What were the key factors that led to your decision to join the NHGRI?

Dr. McBride: I was very happy at Duke University doing research in behavioral change interventions. My concerns were that the mechanisms for funding and peer review limited my creativity. I found myself having to sell an idea and make it fit into what my peers could appreciate as the next logical step in my research. That, in my opinion, homogenized a lot of the science. I think there is an important role for the kind of science that takes an idea with a lot of pilot data and a good reason to work and tests that idea on a large scale. But I also think that we need to be pushing the envelope to develop more innovative approaches to promote healthy lifestyles. It is a very responsible way to use the taxpayers' money. I, however, was getting frustrated by the process and found myself wanting to push the envelope of my research by pursuing higher-risk research ideas. With higher-risk research, however, funding becomes increasingly difficult to obtain. I also felt that behavior change intervention had reached a ceiling in terms of our efficacy. I had reached a point where I could not get 20% of smokers to quit smoking no matter what I did in intervention trials. That percentage was relatively consistent across the board in terms of varied types of behavior change, and the effects were fairly constant across different intervention studies. I thought we needed to find innovative ways to move beyond that ceiling. I believed that genetics and genetic feedback and a better understanding of the genetics that underlie our behaviors might ultimately help us create better interventions and push us over the ceiling. It was a very exciting prospect to think about how genomics could accelerate movement from a disease treatment model of care to a prevention and health promotion model of care.

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JIM: The SBRB has the broad objective to translate genomic discoveries into initiatives that will advance health promotion, disease prevention, and health care improvements. Please describe your vision for the future of the SBRB.

Dr. McBride: We are using a multifaceted approach that has evolved by evaluating where the state of the science is with respect to genetics and how it might broadly improve health care delivery and public health promotion. We spent the first year bringing in

experts from around the country. Because this is such a new area, the number of seasoned experts in the field is limited. We managed to get as many of those as possible together to talk about the unique niche of the SBRB at NHGRI within the DIR. The distinguishing feature of intramural research is that it is charged to do the most innovative high-risk research. With that direction, we asked ourselves, "How might we make the biggest contribution?" We determined that we would take the lead in doing smaller studies that were higher risk and that we would try to model transdisciplinary research. The existing paradigm and framework driving much of public health research are somewhat limited, with the focus on either toxicology or epidemiology or bench science. We determined that we were in a good position, given our size as a relatively small multidisciplinary group who could model transdisciplinary research, to establish a model of social and behavioral research for others around the country. We also had to decide on thematic areas where we might be strongest and prove most effective. We determined we could contribute to genetic services delivery, public health and public health intervention development, and bioethics and social policies. We will naturally try to identify projects that overlap with these areas of focus to capitalize on the expertise of our faculty and make the best use of our limited resources. In addition, there are several intersecting themes addressed by researchers in the branch, including the implications of genomic discoveries and research for health disparities, the ethical and legal implications of genetic research, and strategies for information dissemination to medical and other communities.

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Future directions of the SBRB program include evaluating processes surrounding genetic risk communication to determine how best to convey complex risk messages to maximize comprehension and minimize biased processing; evaluating genetic counseling interventions that optimize decision and behavioral outcomes that can be exported to new situations that may not involve genetic specialists; evaluating channel modalities (eg, tailored print, lay health advisors, Web based); matching target populations; exploring differences in comprehension of risk communication; and assessing uptake of testing and preventive behaviors.

JIM: The National Institutes of Health (NIH) has a strong interest in eliminating health disparities among minority groups. Will the SBRB play a role in accomplishing this goal?

Dr. McBride: That is absolutely one of our major cross-agency areas of focus. We did not want to define this as one of our individual thematic areas because we felt attacking that goal requires broad expertise. We want to infuse all of our research with the goal to reduce or eliminate health disparities. Two concerns arise here. The first surrounds the dissemination of genetic and genomic discoveries. The concern is that genomic information will be confined to those who can afford access to this high level of science and those who have comprehensive insurance. Second, we need to ensure that ongoing genomic research is not limited to certain socially defined groups, where grouping may be used against people. There are also sensitivities that have a historical basis about genetic research and the effects genetic and genomic research may have. So, yes, the need to eliminate health disparities will be a major part of our work.

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JIM: What was involved in creating a new research branch within NHGRI, and how involved were you in determining the mission of the SBRB?

Dr. McBride: The NHGRI brought in a consultant to determine whether or not there was a need to have a dedicated branch of social and behavioral research within the NHGRI. Since I joined the NHGRI, I have been very involved and have done almost all of the planning for the branch. Together with the branch chief of the Division of Intramural Research and our faculty members, we have determined the mission of the program. Our mission is to apply genomic discoveries to improve risk communication and comprehension, genetic counseling methods, and prevention interventions. The program also focuses on understanding how social factors influence genomic discoveries and research and on investigating emerging ethical and public policy implications of genomic research.

JIM: You have stated that SBRB's research portfolio will include four conceptual domains: testing communication strategies for conveying individual risk for developing a genetic condition; developing and evaluating interventions aimed at reducing the risk of disease in those genetically susceptible; translating genomic discoveries to clinical practice; and understanding the social, ethical, and policy implications of genomic research. How did you identify these four areas of focus?

Dr. McBride: The areas of focus were developed during our planning sessions with the experts. But they also reflect the current and potential use of genomics in everyday life. If you analyze the process of how people learn about their genetic makeup and how that information might be used to their benefit and their detriment, the areas of focus clearly stand out as important steps in that process. It is intuitive that those are critical domains, and it is also where the science is right now.

JIM: How many scientists are currently working within the SBRB, and what number will be working in the branch when it is fully staffed? What types of projects are ongoing?

Dr. McBride: We currently have six faculty members with expertise in genetic counseling, public health, bioethics, and social policy research. We will be adding two more in the near term, and we hope to be at 10 when we are fully staffed. There will be a number of research groups within the SBRB. They include a health communications section; a genetic services unit; a public health research section; and a bioethics and social policy unit that includes research ethics.

JIM: In the NIH Roadmap, Director Elias Zerhouni, MD, notes that en-

hanced collaboration between scientists of different disciplines is necessary to solve increasingly complex problems. Collaboration will be critical to the success of the SBRB. What benefits of collaborative research are most relevant and important to NIH scientists?

Dr. McBride: I don't think we should be doing any science that isn't collaborative and bringing different perspectives together. There is no other way to solve complex problems than to interact with other disciplines that are engaged in genomic research by crossing disciplinary boundaries. It's very natural and very balanced to apply other perspectives to social and behavioral research.

JIM: Do you feel that most Americans are aware of the potential of the Human Genome Project to change the way illness is prevented and treated?

Dr. McBride: No, absolutely not. I think there has actually been an overstatement of how quickly genomic discoveries will have an impact on day-to-day health care. Genomic discovery is moving very fast, and change is coming very quickly. The challenge is to assess how long will it take the general public to understand the complexity of the human genome and begin to realize the health benefits of new genomic discoveries. Most of us agree that the pace of genetic discovery is accelerating due in part to the completion of the human genome sequence and that scientists now have ready access to on-line databases of thousands of genetic markers that make it easier to identify the location of genes. But, that doesn't translate immediately into tangible benefits to the public, and that's where our research can make the greatest contributions.

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JIM: What do you feel are the greatest challenges that can and should be addressed through social and behavioral research?

Dr. McBride: The field of social and behavioral research is wide open and evolving rapidly. The greatest challenges will likely be a moving target, because projections of the future are divergent, and, in some cases, polarized. In order to stay at the leading edge of social and behavioral science, we need to be wherever the ball is going in genomics and to identify where the biggest problems are and where there is a need for genomics to help the general population. Our biggest challenge is exploring differences in comprehension of risk communication.