Rob Mitchell, PhD, of Duke University and Jean Cadigan, PhD, of the University of North Carolina-Chapel Hill have conducted a study to measure the understanding of the MURDOCK Study in the Kannapolis/Cabarrus County community. Working with MURDOCK Community Health Project Leader, Ashley Dunham, MSPH, PhD, in Kannapolis, the researchers identified 28 interviewees, 15 of whom joined the MURDOCK Study and 13 who declined participating in the study. After screening responders from an initial contact mailer, two graduate students from the Department of Social Sciences and Health Policy in the Wake Forest University School of Medicine interviewed those participating in this study. “We used a semi-structured interview guide that was largely based on the study we did with EPR (the Environmental Polymorphisms Registry [described below])”, Cadigan said. “This interview guide asked pointed questions, but gave room for participants to go off subject.”

The researchers’ interest in interviewing both those who joined and those who chose not to join the MURDOCK Study stemmed from previous projects at the Center for Genomics and Society (CGS) at the University of North Carolina-Chapel Hill. In one such project, Dr. Cadigan and her colleagues conducted hour-long interviews with approximately 30 individuals who were recruited to join the NIEHS-funded Environmental Polymorphisms Registry (EPR), roughly half of whom agreed to join the EPR study, while the other half did not. The analyses provided in-depth examination of the actual hopes and concerns about participation in the EPR. Relatedly, Dr. Mitchell indicated, “I was interested to see the reactions of people from North Carolina about biobanks, and the MURDOCK Study is much less abstract than the others because it focuses on a particular county…I was also fascinated by the history of the town.” Dr. Cadigan agreed and is intrigued by the idea of “genetic citizenship”. Dr. Mitchell noted, “The MURDOCK Study is just so interesting and brings together so many issues, there was no way we were not going to do a study”. In addition, the researchers were interested in exploring participant and decliner hopes and concerns developing from residents’ understandings of the history of the MURDOCK Study.

Many of the preliminary results from the study were unexpected by the researchers. Drs. Cadigan and Mitchell originally anticipated that the educational differences between EPR participants and MURDOCK participants would be striking, since EPR participants were largely faculty, staff, and students from UNC-Chapel Hill and characterized by relative affluence and advanced educational backgrounds. However, the educational demographics of joiners and decliners of the MURDOCK Study turned out to be quite similar to those in the EPR Study. Of the 15 joiners, 12 had at least a 2-year degree, and 6 had graduate degrees, while of the 14 decliners, 9 had at least a 2-year degree and 2 had graduate degrees. So while there were differences in educational demographics, they were not as remarkable as expected.

Another response the researchers had not anticipated was the great amount of trust the participants had in the MURDOCK Study and its staff. Mitchell stated, “It seems that some were concerned with who owned the samples, but there was much more trust with the MURDOCK Study than with EPR”. Cadigan agreed, “Yes, this was one of the biggest surprises”. In fact, in
the MURDOCK Study, joiners had few fears about the study, and 3 explicitly stated they had no fears about privacy issues, while only 1 decliner expressed fears about data security and privacy.

Other issues, such as the role of money as a motivation to join the MURDOCK Study, produced findings that were very different from the researchers’ previous experiences. More than half of both joiners and decliners noted that the monetary compensation had little or no effect on their decision to participate or not participate in the study and only 1 joiner cited money as a primary reason for joining the study. Cadigan stated, “Money was a big motivating factor in how people decided whether to join the EPR. The EPR requires a lot less of a participant than the MURDOCK Study, so it was surprising the money was not as much of a factor with MURDOCK participants”.

In general, participants were most motivated to join the study because for a number of reasons. They believed they were helping science, had an interest in research or thought they had something interesting about their DNA. They also believed that their participation would benefit the city of Kannapolis or they wanted to help others with a disease condition (if they themselves were diseased). Additionally, participants reported that they had an influential figure in their life join or someone who told them to join. Factors that kept individuals from participating included inconvenience, confusion about study specifics, perceived connections between David Murdock and the MURDOCK Study, or the sense that participants should get something out of joining.

This information is exceedingly important as biobanks are emerging across the country and questions about ethical practices are arising. Cadigan asserted, “There is a general concern that biorepositories are moving towards the direction that if you do not say that you do not want to participate, you participate by default...I want to be supportive to those that are getting people to consent, like the MURDOCK Study”. Mitchell agreed, “We need to analyze how the patients see themselves in relation to the study. It is useful to get a sense of how people understand what they are doing”.