
**Keywords:** Community-Institutional Relations/Cooperative Behavior/Ethics Committees, Research/Health Services Research/Healthcare Disparities/Humans/organization & administration/Translational Medical Research/United States

**Abstract:** Emerging advances in health disparities research include controlled trials and comparative effectiveness studies that are frequently conducted at multiple community and academic sites. Review by different institutional review boards (IRBs) presents a major impediment to the timely and effective conduct of such research. When research involves minority and underserved communities as well as multiple geographic regions, institutional requirements and interpretation of ethical standards may vary substantially. Such variations can complicate the informed consent process and research protocol, and may undermine participant respect and trial quality. In addition, multiple IRB review can lead to unnecessary delays, jeopardizing funding and capacity to perform collaborative projects. In response to these issues, the Research Centers in Minority Institutions (RCMI) Translational Research Network (RTRN) is developing a community-partnered approach to streamlining IRB review across its consortium of 18 RCMI grantee institutions that will ensure compliance while enhancing the quality of health disparities research.


**Keywords:** Adolescent/Adult/African Americans/Aged/Anemia, Sickle Cell/complications/Educational Status/etiology/Faith Healing/Female/Health Care Surveys/Humans/Logistic Models/Male/Marital Status/Massage/Middle Aged/Pain/Pain Management/Patient Satisfaction/Relaxation Therapy/Surveys and Questionnaires/therapy/utilization/Young Adult

**Abstract:** Pain is the clinical hallmark for sickle cell disease (SCD). The objective of this study was to survey the extent and effectiveness of complementary and alternative medicine (CAM) use for pain control among
adults with SCD. Of a total of 227 African-American adults with SCD, 208 (92%) admitted to using at least one type of CAM. The three most common types of CAM were prayer (61%), relaxation technique (44%), and massage (35%). Multiple logistic regression showed that marital status was associated with use of relaxation techniques ($p = 0.044$), and age between 18 and 24 years and at least a high school level of education were associated with use of prayer ($p = 0.008$ and $p = 0.004$ respectively). Our study showed that CAM use is common among adult patients with SCD. Further well designed prospective studies are needed to help develop best practices that emphasize an optimized balance of conventional and evidence based CAM therapies.


**Keywords:** Adult/African Americans/Aged/Aged,80 and over/ethnology/Focus Groups/Genetic Research/Genome-Wide Association Study/Health Knowledge, Attitudes, Practice/Health Literacy/Humans/Middle Aged/Patient Participation/Patient Selection/psychology/Research Subjects/Socioeconomic Factors/Young Adult

**Abstract:** The Jackson Heart Study (JHS) convened focus groups to engage the community in dialogue on participation in the National, Heart, Lung and Blood Institute’s Candidate Gene Resource (CARe) project. CARe, a genome wide association and candidate gene study, required the release of participant phenotypic and genotypic data with storage at NIH for widespread distribution to qualified researchers. The authors wanted to assess the willingness of an African American community to participate in the genetics research, given the past history of bioethical misconduct in ethnic minority communities. The discussion produced the following specific issues of interest: reasons for participants’ interest in genetics research; participants’ knowledge about the JHS; and participants’ knowledge about genetics research and its advantages and disadvantages. Training on genetic issues was also developed for the JHS community and staff.