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Community Engagement and the Resource Centers for Minority Aging Research

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The National Institute on Aging created the Resource Centers for Minority Aging Research (RCMARs) to address infrastructure development intended to reduce health disparities among older adults. The overall goals of the RCMARs are to (a) increase the size of the cadre of researchers conducting research on issues related to minority aging; (b) increase the diversity of researchers conducting research on minority aging; (c) create and test reliable measures for use in older diverse populations; and (d) conduct research on recruitment and retention of community-dwelling older adults for research addressing behavioral, social, and medical issues. Along with this latter goal, the RCMARs developed and maintain academic–community partnerships. To accomplish the recruitment and retention goal, the RCMARs established Community Liaison Working Groups using a collaborative approach to scientific inquiry; this special issue will identify research priorities for moving the science of recruitment and retention forward. In addition, sustainable and efficient methods for fostering long-term partnerships will be identified between community and academia. Evidence-based approaches to the recruitment and retention of diverse elders are explored. We expect this supplement to serve as a catalyst for researchers interested in engaging diverse community-dwelling elders in health-related research. In addition, this supplement should serve as a source of the most contemporary evidence-based approaches to the recruitment and retention of diverse older populations for participation in social, behavioral, and clinical research.

The National Institutes of Health (NIH) is committed to its mission "to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce the burdens of illness and disability" (http://www.nih.gov/about/mission.htm). Despite significant advances in medicine and the behavioral and social sciences, not all persons in our society benefit from advances resulting in improved health, increased longevity, and decreases in disability. Many impediments to these goals are attributable to social factors in American society. The consequences of race, ethnicity, socioeconomic status, and geography are mechanisms through which disparities in health and well-being manifest themselves. To overcome some of these roadblocks, especially for older persons, the National Institute on Aging (NIA) has directed and funded a committed group of researchers for over a decade, through a program called the Resource Centers for Minority Aging Research (RCMARs).

The RCMAR mission is to create an infrastructure to decrease health disparities by: (a) increasing the number of researchers who focus on the health of minority elders; (b) enhancing the diversity in the professional workforce by mentoring minority academic researchers for careers in minority elders' health research; (c) improving recruitment and retention methods used to enlist minority elders in research studies; (d) creating culturally sensitive health measures that assess the health status of minority elders with greater precision; and (e) increasing the effectiveness of interventions designed to improve their health and well-being.

The six funded RCMAR Centers for 2007–2012 are:

The University of Alabama (Richard M. Allman, PI).
The University of Michigan and Wayne State University (James S. Jackson and Peter A. Lichtenberg, PIs).
The University of Pennsylvania (Jerry Johnson, PI).
The University of California—Los Angeles (Carol M. Mangione, PI). The UCLA Center also hosts the RCMAR National Coordinating Center (Janet Frank, Director).
The University of Colorado and the University of Washington (Spero Manson and Dedra Buchwald, PIs).
The University of California—San Francisco (Eliseo J. Perez-Stable, PI).

The RCMARs are structured around “Cores” or “Working Groups,” one of which deals with community liaison functions. This group’s objective is to facilitate working relationships with host communities and to conduct research on recruiting and retaining community members for participation in behavioral, social, and medical research. To advance research in the study of minority recruitment and retention, the Community Liaison groups of the six RCMARs conducted a symposium entitled “Recruitment and Retention Strategies for Minority Aging Research: An NIA Translational Conference to Promote the National Research Council’s Recommendations for Minority Aging Research” prior to the Gerontological Society of America’s annual meeting in November 2008. Many of the articles appearing in this supplement are the product of this symposium. As such, they represent some of the most current scientific knowledge available on this topic.

In addition to articles resulting from the symposium, two of the articles in this issue are the result of research on recruitment and retention conducted by researchers affiliated with Alzheimer’s Disease Centers (ADCs). Another is the work of researchers affiliated with the Health and Retirement Study (HRS). NIA funds 29 ADCs at major medical institutions across the Nation. Researchers at these Centers are translating research advances into improved diagnosis and care for Alzheimer’s disease (AD) patients and conducting research to cure and possibly prevent AD. The HRS, also sponsored by the NIA under a cooperative agreement with the University of Michigan, follows more than 20,000 men and women over 50 years old, offering insight into the changing lives of the older U.S. population. Launched in 1992, this multidisciplinary longitudinal study has become known as the Nation’s leading resource for data on the combined health and economic conditions of older Americans. Because of the nature of both the HRS and the ADCs, issues of recruitment and retention are central to their success.

The RCMAR centers, the ADCs, and the HRS are NIA/NIH funded initiatives. The NIH Revitalization Act of 1993, Public Law 103-43, requires NIH-sponsored research to improve the generalizability of research findings by requiring the inclusion and reporting of the female and minority composition of their research participants as well as a rationale for their selection. Because of the historic underrepresentation of minorities in research, how treatments or preventive interventions will vary in their outcomes across diverse populations cannot be known (Swanson & Ward, 1995). Therefore, minorities need to be adequately represented in study populations in order to ensure that research findings are generalizable to the entire population (Wendler, Kington, Madans, Van Wye, Christ-Schmidt, Pratt, et al., 2006). To date, there has been no systematic analysis to assess the impact of the NIH Revitalization Act (Dikerson, Leeman, Mazure, & O’Malley, 2009). To do so would require all investigators at the conclusion of their grant period to report the actual number of minorities participating in the research.

The barriers to minority recruitment and retention are highly varied and difficult to clarify; therefore, strategies for addressing these barriers are equally difficult to define. The U.S. Public Health Service Study at Tuskegee has come to symbolize ethical misconduct in the context of clinical research and to be considered the root of the distrust African Americans have of research (Corbie-Smith, Thomas, & St George, 2002). Expanding upon this theme, Arean, Alvidrez, Nery, Estes, and Linkins (2003) assert that each culture and community has its own unique barriers and concerns (e.g., mistrust, stigma, burden) regarding research participation. There is no “one-size-fits-all” way to address these issues. The challenge for investigators conducting research with minority populations is to develop recruitment and retention methods tailored to the issues specific to the community.

Consequently, Arean and colleagues (2003) advocate consumer-centered models rather than more traditional methods for increasing minority enrollment in research studies. Traditional methods include overcoming instrumental barriers such as increasing knowledge about the study through the media, providing transportation to the research site, providing monetary incentives to complete follow-up assessments, and minimizing participant confusion by having the same interviewer administer baseline and follow-up assessments. Consumer-centered models typically consist of four necessary activities: (a) consult with community opinion leaders, gatekeepers, and representative consumers when designing their research; (b) include visible staff members who are ethnically similar to, have experience working with, or are members of the target population; (c) anticipate and take steps to alleviate respondent burden; and (d) provide feedback to the target community.

Interestingly, UyBico, Pavel, and Gross (2007) conducted a meta-analysis of 48 studies on recruitment interventions for vulnerable populations (minority, underserved, poor, rural, urban, or inner city) and for which the parent study consisted of an intervention. The recruitment interventions were categorized into four main categories: social marketing, community outreach, referrals, and health system recruitment. Social marketing included mass mailings, mass telephone calls, and media. Community outreach included activities such as church recruitment, contact with community leaders and organizations, community presentations and meetings carried out by the research team, and health screenings. Referrals included contacts such as those from friends, family, or other participants in the study. Health systems recruitment strategies included recruitment by the health care provider or allowing research staff to approach potential subjects in clinical settings or the use of medical records/registries to identify patients.

Only the community outreach interventions proposed by UyBico and colleagues (2007) seemingly contain components of the consumer-centered model as described by Arean and colleagues (2003). However, UyBico and colleagues found no strategy to be more successful than others and that community outreach alone may be less successful than other strategies. They concluded that further work, such as that reported in this Special Issue of *The Gerontologist*, is needed to identify evidence-based strategies for increasing minority enrollment in research studies.

In addition, Wendler and colleagues (2006) conducted a meta-analysis of the literature and identified 20 health research studies that reported consent rates by race or ethnicity for more than 70,000 individuals. Their goal was to determine the extent to which racial and ethnic minorities, especially in the United States, are less willing than others to participate in health-related research. The researchers found very small differences in the willingness of United States racial and ethnic minorities, most of whom were African Americans and Hispanics, to participate in various types of health research (clinical interventions, surgical interventions, interviews) compared with non-Hispanic Whites. They concluded that racial and ethnic minority groups in the United States are as willing as non-minority individuals to participate in health research and suggest that willingness to enroll may be a function of the interaction between characteristics of a study and racial or ethnic identity.

The most current meta-analyses of research in the area do not offer a clear picture of how to improve the recruitment and retention of minority elders in research. Further model-based research is needed to determine the role of potential participant characteristics, the role of study characteristics, and how the two interact. This supplement is intended to provide additional research evidence to the *Science of Inclusion* (Curry & Jackson, 2003) and to motivate investigators to continue to move this area of science forward.

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References

Arean, P. A., Alvidrez, J., Nery, R., Estes, C., & Linkins, K. (2003). Recruitment and retention of older minorities in mental health services research. *The Gerontologist*, *43*, 36–44.

Corbie-Smith, G., Thomas, S. B., & St George, D. M. M. (2002). Distrust, race, and research. *Archives of Internal Medicine*, *162*, 2458–2463.

Curry, L., & Jackson, J. (Eds.), (2003). *The science of inclusion. Recruiting and retaining racial and ethnic elders in health research*. Washington, DC: The Gerontological Society of America.

Dickerson, D. L., Leeman, R. F., Mazukre, C. M., & O'Malley, S. S. (2009). The inclusion of women and minorities in smoking cessation clinical trials: A systematic review. *American Journal of Addictions*, *18*, 21–28.

Swanson, G. M., & Ward, A. J. (1995). Recruiting minorities into clinical trials: Toward a participant-friendly system. *Journal of the National Cancer Institute*, *87*, 1747–1759.

UyBico, S., Pavel, S., & Gross, C. P. (2007). Recruiting vulnerable populations into research: A systematic review of recruitment interventions. *Journal of General Internal Medicine*, *22*, 852–863.

Wendler, D., Kington, R., Madans, J., Van Wye, G., Christ-Schmidt, H., Pratt, L. A., et al. (2006). Are racial and ethnic minorities less willing to participate in health research? *PLoS Medicine*, *3*, 201–210.