

Conclusion

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Advancing the Science of Recruitment and Retention of Ethnically Diverse Populations

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We highlight several critical challenges that must be addressed to accelerate the advancement of the science on recruitment and retention of ethnically diverse older adults into health research. These include the relative lack of attention by researchers to methodological issues related to recruitment and retention of ethnically diverse populations and the inadequacy of funding to advance systematically this field. We describe strategies used by the Resource Centers on Minority Aging Research and other National Institute of Aging-funded programs to advance the science of recruitment of ethnically diverse older adults. Finally, we propose a set of broad recommendations designed to generate a body of evidence on successful methods of recruitment and retention of ethnically diverse populations in health research. To eliminate health disparities and better understand aging processes in ethnically diverse populations, much more research is needed on effective strategies for increasing minority enrollment in health research. Comparative effectiveness research on more intensive recruitment and retention methods, which are often needed for including diverse populations, will require dedicated funding and concerted efforts by investigators.

Key Words: Health research, Enrollment, Racial and ethnic minorities, Race, Ethnicity

The National Institutes of Health (NIH) Revitalization Act of 1993 and the Agency for Healthcare Research and Quality Healthcare Research and Quality Act of 1999 identified recruitment and retention of diverse populations as a priority for clinical researchers. ([Agency for Healthcare Research and Quality, 2003](#); [NIH, 2001](#)) The need to include ethnically diverse groups in health research will grow even more acute as the United States becomes increasingly multicultural.

Systematic reviews have examined factors affecting the equitable representation of minority groups in research ([Ford et al., 2008](#); [Lai et al., 2006](#); [UyBico, Pavel, & Gross, 2007](#); [Yancey, Ortega, & Kumanyika, 2006](#)). These reviews share one overarching recommendation, that is, the need for more systematic research to test the efficacy of specific methods, with greater methodological rigor, in specific subpopulations. The recruitment literature on older ethnically diverse adults is particularly limited.

The Resource Centers for Minority Aging Research (RCMARs) were established originally by the National Institute on Aging (NIA), with co-funding from the National Institute of Nursing Research, and the Office of Research in Minority Health. The RCMAR program is currently funded by the NIA and the National Center for Minority

Health and Health Disparities, to address health disparities among older ethnic minority adults. The RCMARs foster academic-community partnerships and conduct research on recruitment and retention of older ethnic minority adults for health research to develop evidence-based approaches. Some of the challenges and successes in advancing the science of recruitment have been described in this supplement to *The Gerontologist* entitled, “The Science of Recruitment and Retention among Ethnically Diverse Older Adults.”

In this commentary, we aim to highlight several critical challenges that must be met to accelerate the advancement of the state of the science on recruitment of ethnically diverse older adults for health research. These include the relative lack of attention by researchers to methodological issues related to recruitment and retention of ethnically diverse populations and the inadequacy of funding to advance systematically this field. Then, we will illustrate some of the strategies used by the RCMARs and other NIA-funded programs to advance the science of recruitment of ethnically diverse older adults. Finally, we will propose a set of broad recommendations designed to generate a body of evidence on successful methods of recruitment and retention of ethnically diverse populations in health research.

Lack of Attention by Health Researchers to Issues of Recruitment and Retention of Ethnically Diverse Populations

The paucity of evidence on effective recruitment and retention methods for use with ethnically diverse populations is largely a reflection of their de facto exclusion in research and the omission by health researchers of published ethnic group-specific data on recruitment and retention results. Several systematic reviews have documented the general lack of attention by clinical researchers to enrolling and reporting on ethnically diverse groups in studies. For example, one review that examined more than 700 articles published between 1970–2003 on obesity-related lifestyle interventions, identified only 23 that included a large enough sample of an underserved ethnic group to enable ethnic group-specific analyses and only 5 of these presented ethnic group-specific outcomes data (Yancey et al., 2004). Another review of 261 Phase III cancer prevention and treatment trials from 1990 to 2000 found that, although 92% of these trials reported the age and

gender composition of their samples, race/ethnicity was reported in only 35% of treatment and 54% of prevention trials. None of the trials used race or ethnicity in their selection criteria, whereas gender was specified in 44% and age in 29% of the trials’ selection criteria (Swanson & Bailar, 2002). Finally, a review of arthritis-related behavioral intervention studies from 1997 to 2008 found that only 11 of the 25 studies provided data on the racial/ethnic diversity of their samples and only 2 of these stratified their results by White and minority participants (McIlvane, Baker, Mingo, & Haley, 2008). Inattention to recruitment of ethnic minority groups and failure to report on the racial and ethnic group composition of samples (and stratified outcomes data) limits our ability to address health disparities.

Inadequate Funding of Recruitment- and Retention-Specific Studies

Despite the importance of establishing evidence-based recruitment strategies, federal funding opportunities to support rigorous research on the science of recruitment and retention in diverse populations are lacking. To illustrate the lack of federal funding opportunities for studies of recruitment or retention methods in health research, we conducted searches using two major Web sites listing federal funding opportunities and solicitations: the Federal Business Opportunities (FedBizOpps.gov) and NIH Office of Extramural Research (<http://grants.nih.gov/grants/guide/>) Web sites. We used search terms of “recruitment OR retention AND research,” searching for active and inactive funding opportunities between 1992 and September 2010.

The FedBizOpps.gov search yielded 857 opportunities. Reviewing the title and synopsis of each one identified no opportunities that specifically requested research studies to test the effectiveness of recruitment or retention methods. Two that were closest to this intent were a contract award opportunity to generate a representative sample for the Healthy Aging in Neighborhoods of Diversity across the Life Span Study (solicitation number: 260-03-15) and a solicitation for an AIR National Guard Recruiting and Retention CD-ROM Planning Tool to assist recruiters in tracking progress toward recruitment goals (solicitation number: W9133N-04-CD-ROM). The search of the NIH Office of Extramural Research Web site yielded nine funding opportunities. None focused

on studying the effectiveness of recruitment or retention methods.

Accumulating an Evidence Base on Recruitment and Retention of Ethnically Diverse Older Adults

The RCMARs and other NIA-funded programs have implemented strategies to build an evidence base on effective recruitment strategies in diverse populations in the face of limited funding. One of these strategies involves conducting nested studies of recruitment methods within funded health research studies. For example, at the University of California San Francisco RCMAR, called the Center for Aging in Diverse Communities, researchers have conducted randomized trials of several types of supplemental recruitment materials that have been nested within patient-reported quality of care studies, such as the addition of pamphlets that describe the nature of research or invitation letters that are culturally tailored (Napoles-Springer, Fongwa, Stewart, Gildengorin, & Perez-Stable, 2004). Conducting comparative effectiveness studies of recruitment and retention methods will require targeted funding, but in the absence of such funding, conducting nested recruitment studies is a useful interim strategy. However, nested studies without supplemental funding are only economically feasible for low-intensity recruitment methods.

Another strategy that is used within funded studies is to conduct supplemental analyses related to recruitment and retention outcomes. For example, such analyses have included reporting of enrollment rates stratified by race/ethnicity and stage of recruitment or retention (e.g., contact attempt, contact, invitation, enrollment, maintenance; Napoles-Springer, Santoyo, & Stewart, 2005; Ofstedal & Weir, 2011) or examining participant and site characteristics associated with retention (Manson et al., 2011). Formative research can also be used to collect data prior to (or even after) studies to examine barriers and facilitators of participation of underrepresented groups (Napoles-Springer et al., 2000; Williams, Meisel, Williams, & Morris, 2011).

The RCMAR at the University of Michigan/Wayne State University, called the Michigan Center for Urban African American Aging Research, has developed a registry of research study volunteers composed mostly of older African Americans (Chadiha et al., 2011). If multiple research centers could share the costs to support the development

and maintenance of such registries, this strategy might prove to be especially cost-effective across centers. Moreover, registries may serve as a resource for creating samples of older adults from underrepresented groups, particularly racial/ethnic minority persons, and for collecting data on their health status and outcomes of care. A more resource intensive approach adopted by the NIA-funded Alzheimer's Disease Research Center at Washington University involved setting up an African American Outreach Satellite, which conducts strategic outreach and recruitment programs and training for community health care providers (Williams et al., 2011).

Recommendations to Advance the Science of Recruitment and Retention

Taken together, these creative strategies are beginning to inform future efforts to recruit and retain vulnerable populations in research. Nonetheless, much work remains to be done if we are to eliminate health disparities in older adults. The lack of funding for recruitment studies helps explain the preponderance of observational studies focused on this topic. Experimental studies in the recruitment literature that rigorously test recruitment or retention methods are the exception, despite the valuable evidence they contribute (Kiernan, Phillips, Fair, & King, 2000; Ramirez et al., 2008, 2008; Wenzel et al., 2008). Although formative and observational recruitment and retention studies are informative and essential, the insights they provide and methodological questions they raise can be addressed more definitively in some cases, using experimental methods. Tracking the cost-effectiveness of recruitment and retention methods is also vital.

Reflecting on the content of this supplement and our experiences through the RCMAR program, we present in Table 1 a set of recommendations that would significantly advance the science of recruitment and retention in diverse populations. The recommendations are listed in order of least to most resource intensive.

A requirement of funded studies that enroll a substantial proportion of an ethnic minority or other vulnerable group should be that investigators report stratified enrollment rates, as well as unique recruitment challenges and solutions within population subgroups. When applying for funding or even after studies are funded, investigators can design nested randomized trials or other types of

Table 1. A Summary of Recommendations for Advancing the Science of Recruitment and Retention of Ethnically Diverse Populations in Health Research Organized From Least to Most Resource Intensive

1. Investigators track and report enrollment rates stratified by race/ethnicity, related challenges, and solutions.
2. Investigators conduct nested studies of the effectiveness of recruitment or retention within other health research studies.
3. Funding opportunity announcements for primary data collection studies include a request for investigators to incorporate a nested study that compares the effectiveness of multiple methods of recruitment and/or retention, especially studies that include underrepresented groups.
4. Funding agencies appropriate targeted funding to investigate specific methodologically challenging recruitment issues, e.g., identifying alternative incentives for recruiting groups that have been discriminated against or that are impoverished in longitudinal cohort studies that may have limited funding to pay monetary incentives to participants.

recruitment studies within the larger substantive study that is the focus of the proposed project. Similarly, funding agencies can incorporate a relevant recruitment or retention topic within the scope of research topics specified in funding opportunity announcements. Finally, just as special funding initiatives have addressed the need for measurement studies to develop innovations in measures of complex behavioral constructs (PAR-08-212 Methodology and Measurement in the Behavioral and Social Sciences; <http://grants.nih.gov/grants/guide/pa-files/PAR-08-212.html>), funding agencies can create targeted recruitment initiatives. These initiatives are especially indicated in the case of large population-based cohort studies involving underrepresented groups, where biological specimens or burdensome procedures are required that can impose particular hardships on participants. A cost-effective way to test recruitment strategies is for funding agencies to offer supplemental funding to nest these studies within larger studies.

Conclusions

To eliminate health disparities and better understand aging processes in ethnic subpopulations, much more research is needed on effective strategies for increasing minority enrollment in health research. Unless there are concerted efforts (set asides) to provide funding to test the effectiveness of specific strategies in underrepresented groups and researchers devote attention to these issues, scientific progress toward identifying the most promising strategies will advance slowly and in a piecemeal fashion. Comparative effectiveness research on more intensive recruitment and retention methods, which are often needed for including ethnically diverse populations, will require dedicated funding and concerted efforts by investigators.

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