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## Strategic Planning for Recruitment and Retention of Older African Americans in Health Promotion Research Programs

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### Abstract

The purpose of this study was to 1) describe a strategic plan for recruitment and retention used in conducting eye health education research with African-Americans living in urban and rural areas of Alabama and 2) characterize recruitment and retention patterns for this community-based project. We evaluated an eye health education program tailored specifically to older African Americans. InCHARGE© was designed to promote eye disease prevention by conveying the personal benefits of annual, dilated, comprehensive eye care and teaching strategies to minimize barriers to regular eye care. The InCHARGE© program or a social contact control program was delivered at 20 senior centers in predominately African American urban and rural communities. From pooled data across three studies, 380 African Americans completed a questionnaire about knowledge and attitudes/beliefs about eye disease and eye care before the program and by telephone at either 3 or 6 months after the presentation. The project consisted of 4 phases and a total of 10 strategic objectives for recruitment as well as retention of older African Americans that were implemented in a systematic fashion. Overall, retention rates for follow-up at either 3 or 6 months were 75% and 66% respectively. African Americans from rural areas were more likely to be lost to follow-up compared to those from urban areas. We discuss the benefits of utilizing a strategic plan that serves to address problems with underrepresentation of minorities in clinical research.

### Keywords

health promotion; recruitment; retention; African Americans; older adults; health disparities; minorities; underserved

## INTRODUCTION

Unfortunately, racial and ethnic minority groups have been significantly under represented in health-related research compared to their burden of disease and representation in the United States population (Heiat & Gross, 2002; Killien et al., 2000; McNeilly et al., 2000; Murthy, Krumholz, & Gross, 2004). Efforts to minimize disparities through research have been limited by low levels of participation of racial/ethnic minority populations in research.

This status of affairs has fostered a body of research aimed at understanding barriers and apprehensions among older African Americans to participating in clinical research (Dancy, Wilbur, Talashek, Bonner, & Barnes-Boyd, 2004; Dennis & Neese, 2000). Some of the barriers include determinants such as historical events and mistrust of health-related research, lack of cultural relevancy and competency, institutional and internalized racism, lack of knowledge about clinical trials, fear of exploitation, and lack of access to care (Brondolo, Rieppi, Kelly, & Gerin, 2003; Dancy et al., 2004; Dennis & Neese, 2000; Gooden et al., 2005).

From a historical perspective, health disparities among African Americans can be traced back to a legacy of slavery, racism, oppression, inequality, and social discrimination (Abrums, 2004; Griffith, Johnson, Ellis, & Schulz, 2010; Valentine, 2008). Unfortunately, many of these problems are still pervasive to this day and continue to shape the behavioral responses among African Americans and their willingness to participate in research. Researchers are sometimes viewed as outsiders because of a social disconnect between differences in the community, healthcare environment, and individual factors (Dennis & Neese, 2000; Mwachofi & WaMwachofi, 2010). Other issues impeding recruitment/retention among African Americans are related to the lack of strategies that address these types of barriers, researchers' opinions about the recruitment of African Americans, lack of investigator confidence in explaining research in culturally appropriate terms, failure of investigators to understand perceptions of health beliefs, lack of appreciation regarding fear of exploitation, and/or research design and implementation (Durant, George, Willimans, Blumenthal, & Corbie-Smith, 2007; Shavers & Lynch, 2000; Stone, Mauch, & Steger, 1998).

This underrepresentation in health research among African Americans is particularly unfortunate given the amount of evidence documenting the benefits of health promotion programs. Health promotion efforts are designed to raise health awareness/knowledge and improve health behaviors (e.g., risk for a preventable disease, medication adherence, physical activity, dietary/food intake) (Dreer et al., under review; Dreer et al., 2013; Satcher et al., 2006). Thus, these programs show promise in ultimately preventing health conditions and/or secondary health complications (e.g., death, vision loss/blindness, hospitalizations), thus eliminating health disparities.

In order to continue to address the pervasiveness of under inclusion of African Americans in health promotion research, more studies examining recruitment/retention strategies are needed. While a few models aimed at enhancing recruitment have been proposed (Alvarez, Mayorga, Feaster, & Mitrani, 2006; Loftin, Barnett, Bunn, & Sullivan, 2005; Mwachofi, 2012), supporting evidence regarding the effectiveness of these models in recruiting and retaining minority participants is lacking (Lang et al., 2013). Thus, the purpose of this article is to 1) describe a strategic plan for recruitment/retention we used in conducting community-based eye health promotion research with older African-Americans and 2) evaluate recruitment/retention characteristics for this project in the Deep South that has historical roots in racism and distrust in health care (e.g., Tuskegee Study).

## METHODS

We conducted a pooled analysis of data from three studies approved by our Institutional Review Board and conducted in accordance with the provisions of the Declaration of Helsinki. In the following sections, we describe four phases with a particular emphasis on our strategic plan to increase recruitment/retention.

### Phase 1: Problem Identification

**Review of Existing Evidence: Eye Diseases and African Americans.** Accumulating research has shown that rates for eye diseases such as glaucoma, cataracts, and diabetic retinopathy and blindness among older African Americans are 2 times higher than those of Caucasians (Tielsch et al., 1991; West, Munoz, Schein, Duncan, & Rubin, 1998). If these types of eye diseases and complications were detected and subsequently treated earlier, much of the problems with vision impairment resulting from such eye conditions could be significantly delayed, reversed, or possibly prevented with ophthalmic treatments (Higginbotham et al., 2004; Kass et al., 2002; Sommer et al., 1991). Benefits to eye health and quality of life have been reported for early detection and treatment of various eye conditions (Coleman, Yu, Keeler, & Mangione, 2006; Owsley et al., 2007). It is also accepted that elimination of health disparities for eye diseases requires the development of consumer informed, health education programs that are culturally relevant to the issues experienced by older African Americans themselves (Dreer et al., 2013; Elish, Royak-Schaler, & Higginbotham, 2011). Thus, understanding the reasons and barriers related to eye care utilization would provide important information necessary for guidance in the design of meaningful interventions or programs to increase routine eye health care utilization among older African Americans.

**Focus Groups: Input from Stakeholders—**Our next step was to conduct 17 focus groups examining the perceived barriers and attitudes about vision and eye care among older African Americans as well as among ophthalmologists and optometrists serving their communities. The barrier-to-care problem most frequently cited by both African Americans and eye care providers was transportation. The next most common problems mentioned by African Americans were trusting the doctor, communicating with the doctor, and the cost of eye care; and for eye care providers, the next most common problems were cost, trust, and insurance. With respect to older African Americans' comments on their attitudes about vision and eye care, these comments were predominantly positive (69%), highlighting the importance of eye care and behavior in their lives and attitudes that facilitated care. However, when eye care providers relayed their impressions of African Americans' attitudes about vision and eye care, their comments were largely negative (74%) centering on concerns and frustrations that older African Americans did not have attitudes or engage in behavior that facilitate eye care. For greater detail, see Owsley et al., 2006.

The advantage of using this type of approach is that it took into consideration the concerns directly voiced from older African Americans regarding their experiences. We recognized that in order to overcome conceptual barriers related to recruitment and retention as identified in the literature, we needed a comprehensive understanding of our target

population's experiences, culture and social context, and attitudes and beliefs related to eye care.

## Phase 2: Program Development

Next, we met as a team of researchers, clinicians, and community members to identify realistic strategies for overcoming the barriers. We discussed potential cultural issues (e.g., mistrust in research; attitudes toward health prevention strategies and health practices; health literacy; language, values, and customs). We created materials with input from African American community members and leaders so that information was meaningful and culturally-relevant. For example, we used quotes from community members and focus groups as well as their pictures, with permission from participants. We incorporated motivational/spiritual examples into the curriculum messages. Lastly, the materials were created at an 8<sup>th</sup> grade reading level and included bullet points so that the information was brief and easy to view. This was intended to enhance engagement in the materials.

The resulting program we developed is called InCHARGE© which stands for *In Communities Helping African Americans Receive General Eye Care* (Owsley et al., 2013; Owsley et al., 2008; Owsley et al., 2012). Our community-based program was designed for administration in a group setting in the community, and its content is targeted for older African Americans. The length of the program lasts approximately 45 minutes. The specific topics addressed include understanding the importance of prevention, what constitutes a comprehensive eye exam, how to find an eye doctor and actually get there, one's rights as a patient, how to cover the cost, and how to effectively communicate and build trust with an eye doctor. As part of the program materials, each participant is given a program workbook that is a resource they can take home, pen, and tote bag. The primary message of InCHARGE© is eye disease prevention through the annual, dilated comprehensive eye examination and strategies for removing barriers to care. It is delivered by a trained health educator. In the last of our three studies, we conducted a randomized trial that used a social contact control program (Owsley et al., 2013). The message in this program included a focus on physical activity and did not include any discussion of eye care or eye health. For detailed findings regarding the impact of the program, see Owsley et al., 2008; Owsley et al., 2012; and Owsley et al., 2013.

## Phase 3: Program Feasibility/Planning

Once the health promotion program was finalized, we conducted two preliminary studies to establish feasibility and one clinical trial to evaluate the impact of InCHARGE© (Owsley et al., 2008; Owsley et al., 2012). The principal investigator (PI) and project staff met to discuss the project aim, logistics, project staff assignments, and establish a strategic plan for recruitment/retention. Our team was sensitive to the issues related to recruiting in a region with a history of being subjected to exploitation in research (i.e., Tuskegee Study). Specific ways in which staff were sensitive included the following: the staff had an awareness of the lessons learned from the focus groups and the problem in this area of health research; were involved in the interactions with community leaders/members; obtained input from African American community members/leaders when adapting program and recruitment brochures so that they were culturally meaningful; prepared for how to discuss concerns about research

in general as well as the historical issues in research among African Americans in the south, and role-played recruitment procedures and delivery of the curriculum among a small group of African Americans. Resulting from this work, we developed systematic objectives for recruitment and retention (see Tables 1 and 2).

In addition to our community partners, our research project personnel and staff included the principal investigator, biostatistician, a project coordinator (African American woman with training in community health education), and research assistants. The study procedures were discussed and involved having participants complete a brief questionnaire (attitudes, beliefs and perceived barriers regarding eye care) before the InCHARGE© program or general health program (social contact control) presentations began. Then depending upon the requirements for the three separate studies, either 3 months or 6 months after the presentation, participants were telephoned and the questionnaire was repeated.

#### **Phase 4: Program Implementation**

On the day of the program, the project coordinator and staff arrived early to prepare materials and the room to be used for the program administration. All interested older adults had the option of attending. After the program date, we followed up by telephone with the senior center director to discuss the program, receive feedback, and discuss ways we may have improved the program. In longitudinal studies, regardless of the time frame, it is important to maintain this type of partnership, particularly if researchers may need to call upon staff requesting assistance in obtaining difficult to reach study participants. Upon completion of the project, we continued to maintain contact with center agencies. We felt this was an important step in following through on our partnership with communities to help their members. We informed them of study results and summarized findings for their staff and made ourselves available for eye health presentations at other locales in the community.

## **RESULTS**

### **Recruitment Characteristics**

The results of our outcome evaluation of the eye health promotion program are reported elsewhere (Owsley et al., 2013; Owsley et al., 2008; Owsley et al., 2012). Three-hundred and eighty adults attended our presentations. Group size at the 20 participating senior centers varied from 9 to 34 participants ( $M = 19$ ,  $SD = 5.45$ ). The average age was 76 years old ( $SD = 9.27$ ) and ranged from 46 to 104 years old. The majority of the enrollment sample consisted of women ( $N = 304$ , 80%) in comparison to men ( $N = 76$ , 20%). All 380 attendees provided responses on the pre-event questionnaire and sat through the health presentation. Because any member of the center could enter the room and listen to the presentation, 9 participants were determined as ineligible following the presentation due to the following reasons; 1 was Caucasian and the study was focused on eye health in African Americans, 5 were younger than age 60, and 3 were unable to communicate due to hearing loss or language problems. Communication and hearing exclusion criteria were used in this initial study in order to determine the efficacy of the program. If the program were deemed effective, further modification of the program delivery would be made to reach those with

disabilities or language barriers (e.g., incorporation of study partners/family members, translators, etc.).

### Retention Characteristics

Table 3 highlights the demographic characteristics for those who were retained in the sample at follow-up (3 or 6-months depending upon the study requirement). The average age of participants was 75 years old ( $SD = 8.28$ ) and the majority were women ( $N = 220$ , 83%). Two-hundred and sixty four participants out of the eligible 371 participants completed post-program follow-up (71% overall retention rate) with 147 completing a 3-month post-program follow-up (75% retention rate at 3-month follow-up), and 117 participants completing a 6 month post-program follow-up (66% retention rate at 6 months). It took, on average, 2-telephone attempts to reach persons who completed any follow-up ( $SD = 1.90$ ). The number of attempts to reach those who completed a follow-up ranged from 1 to 14 telephone attempts. The average, broken down by 3-month follow-up, was 2 attempts ( $SD = 2.20$ , range 1–14 calls) and the same for 6-month follow-up ( $SD = 1.40$ ).

The overall loss to follow-up for the pooled sample was 29% ( $n = 116$ ). One-hundred and sixteen participants out of 371 eligible participants did not complete a follow-up. For those who did not complete a 3-month follow-up, the loss to follow-up rate was 25% ( $n = 50$ ) and 34% ( $n = 66$ ) for 6-months. The most frequently cited reason for incomplete follow-up data overall was due to an invalid or disconnected telephone number (33%) followed by severe cognitive impairment ( $n = 20$ , 18%), other reasons ( $n = 18$ , 17%), no answer ( $n = 16$ , 14%), refused ( $n = 15$ , 13%), left message (voicemail or with a person) ( $n = 4$ , 3.5%), deceased ( $n = 3$ , 2.5%), and busy signal (1%). For 3 month follow-up, incomplete data was also due to an invalid or disconnected telephone number ( $n = 15$ , 30%), refused ( $n = 10$ , 20%), severe cognitive impairment ( $n = 8$ , 16%), other reasons ( $n = 7$ , 14%), no answer ( $n = 5$ , 10%), deceased 3 (7%), busy signal (1, 1%), and left message ( $n = 1$ , 1%). For 6-month follow-up, incomplete data was also primarily due to an invalid or disconnected telephone number ( $n = 23$ , 35%) followed by severe cognitive impairment ( $n = 12$ , 18%), other reasons ( $n = 12$ , 18%), no answer ( $n = 11$ , 17%), refused ( $n = 12$ , 18%), or left message ( $n = 3$ , 4%).

### Retention Among Rural versus Urban Centers

Table 4 highlights the retention characteristics by geographic location. One-hundred and twelve (29%) of the participants were from 5 rural centers and 268 (71%) were from 15 urban centers.

### Rural Centers

The average age of participants from the rural centers was 74 years old ( $SD = 10.12$ ) and the majority were women ( $N = 61$ , 81%). Rural participants completed a 3-month follow-up only. Seventy-five out of the 105 eligible rural participants (67% overall retention rate) completed the 3-month follow-up. The average number of telephone attempts to contact rural participants to complete the 3-month follow-up was 2 ( $SD = 2.40$ ). The loss to follow-up rate was 29% ( $n = 37$ ) among rural participants who did not complete a follow-up. The majority of rural participants who did not complete a 3-month follow-up were women ( $n = 21$ , 57%) and  $n = 16$  (43%) were men. The most frequently cited reason for rural



participants not completing 3-month follow-up was due to an invalid or disconnected telephone number ( $n = 14$ , 38%) followed by severe cognitive impairment ( $n = 9$ , 25%), other reasons ( $n = 6$ , 16%), no answer ( $n = 3$ , 8%), left message ( $n = 3$ , 8%), or they refused ( $n = 2$ , 5%).

### Urban Centers

The average age of participants from urban centers was 76 years old ( $SD = 8.45$ ) and the majority were women ( $N = 159$ , 84%). One-hundred and eighty-nine out of the 262 eligible urban participants completed post-program follow-up in general (72% overall retention rate) with  $n = 72$  out of 85 eligible participants completing a 3-month post-program follow-up (85% retention rate at 3-month follow-up), and 117 participants out of 177 eligible participants completing a 6-month post-program follow-up (66% retention rate at 6-months). The average number of telephone attempts to complete a 3 or 6-month follow-up was 2 telephone calls ( $SD = 1.99$ , 1.40 respectively). The overall loss to follow-up rate among urban participants was 28% ( $n = 79$  out of 262 eligible urban participants). The loss to follow-up rate increased from 15% ( $n = 13$ ) at 3-month follow-up to 34% at 6-month follow-up among urban rural participants.

## DISCUSSION

In this paper, we described four phases for our community-based health promotion program development, along with our strategic plan for enhancing recruitment and retention when conducting research with older African Americans in the Deep South that has historical roots in racism. The findings indicate successful recruitment as evidenced by the high proportion of older African Americans who participated in this community health promotion research project. The success of enrollment for the three pooled studies might be attributed to the use of 1) a proactive, strategic recruitment plan, 2) the mutually beneficial relationships that were developed and fostered throughout the study with the urban and rural community agencies, and 3) community agency buy in. The number of persons with incomplete post-program follow-up at 3 or 6-months was relatively high, suggesting greater attention needs to be focused on alternative retention strategies over and above what we did for this study. Our strategies for retention included persistent phone calls, dissemination of our contact information, outreach to community agencies, flexibility of scheduling and/or rescheduling missed calls, and mailing out reminder letters to difficult to reach participants.

With regards to the relatively lower retention, the reasons for this rate are somewhat unclear. In retrospect, we could have used more proactive efforts aimed at enhancing retention such as performing the follow-up data collection at the senior centers, having center staff attempt to contact difficult to reach participants, and/or obtaining permission at the time of enrollment for an alternative contact person. Also, our program was designed as a one-time event. Perhaps, ongoing contact might be needed to not only enhance the importance of the program curriculum as well as behavior change but to also indirectly continue to build trust and maintain a relationship with participants, thereby potentially enhancing the likelihood individuals stay in the study and complete follow-up calls. Another reason for a slightly lower retention rate might have been tied to the fact that the program was not individually

tailored. Tailoring approaches often makes programs more interactive and relevant to individuals' circumstances (Dreer et al, under review). Another potential reason might be that individuals in group settings are sometimes afraid to bring up questions or group dynamics come into play that interfere with meaningful interaction. Thus, individually meeting with participants before or after the presentation might have been beneficial. It is also unclear as to how long study posters and brochures remained visible in the centers that could have served as another cue or reminder about the follow-ups. Lastly, another potential reason for lowered retention might have been due to participants potentially feeling embarrassed if they were unable to seek an annual comprehensive eye examination by the time of the follow-up call. It could be that incorporating such an examination into the health promotion program (or a video to show) could have allayed any fears or hesitations about participating in the procedure. However, it should be noted that the brochures did have pictures. Assuch, these issues should be considered when working with older African Americans in community-based health promotion research.

There are few aspects of research design that are as important as to how to effectively recruit/retain minority participants in health research. Recruitment and retention efforts require the same level of attention to the research process as does the research design and data analysis (Dancy et al., 2004). Implementing a strategic plan, such as the one we described, represents a useful approach for enhancing representation and retention among older African Americans in health research. While some approaches for research have traditionally relied upon mailing advertisements, telephone solicitation, recruitment within traditional settings (e.g., hospitals/clinics), or public databases/registries to recruit participants, our approach represented a more interactive approach in that we worked directly with stakeholders (e.g., community agency leaders and African American community residents). This active, collaborative effort has become an increasingly valuable in order to reduce health disparities among African Americans (Satcher et al., 2006). Successful recruitment in service-oriented centers requires understanding the procedures and processes of how agencies serve their community members.

Meeting with community leaders as well as well as community members (stakeholders) on their own turf and seeking their involvement in research projects is one important step in conducting community-based research. While it is unclear from the data, cultural adaptations to the study materials, race/ethnic matching of project staff and participants, recruiter experience, and incorporating meaningful information from the focus groups into the program content may have also positively influenced study participation and retention. Initially, we were cognizant of the fact that we did not understand the complexity of the issues related to the barriers associated with eye care among older African Americans. Thus, conducting focus groups as a first step allowed us to 1) develop trust with this particular population and 2) learn directly from the consumers of eye care themselves what their unique experiences were and why they did not utilize health care. Without such knowledge or developing a program based on provider assumptions regarding program content, it is possible that such retention rates might have been much lower than what was observed in this study.



While the average number of telephone attempts before making contact was relatively low, the range was up to 14 telephone attempts made. This suggests that persistence on the part of staff may have been an important strategy. Our staff modified days and times of calls (evenings/weekend) in order to reach individuals. Interestingly the main reason for loss to follow-up was due to an invalid telephone number(s), which may stem from the economic challenges of this population. While we provided participants with our contact information in the event their contact information changed, we recognize that other strategies could have also been implemented (i.e., letter mail outs, contacting agency staff for changes in contact information).

Another finding noteworthy for discussion was the fact that a larger percentage of women in comparison to men participated. Based on other research, we anticipated there would be a greater percentage of women. However, this was somewhat larger than expected. It may be that more women attend the community agencies for social interaction compared to men. Another potential explanation is from other recent research that examined factors related to non-participation in research among African Americans and found that men with knowledge of the Tuskegee Syphilis study were 50% less likely to be willing to participate in research compared to those who had not heard of the study (Lang et al., 2013). Regardless, more needs to be done to enhance recruitment efforts for African American men.

Like other collaborative research teams, we faced a few challenges. In building trusting partnerships, we had to keep in mind that our partners had different perspectives on the importance of the research process versus service. We also were cognizant of the fact that even when we were given permission to conduct research in the agencies, we were “visitors”. To strengthen our working relationship it was important to engage in active participation, listening, and responding to the needs of our coalition partners versus focusing on any limitations or obstacle. In doing so, we found that it helped to enhance our credibility. Despite these minor challenges, we found that conducting an eye health education program research project in community settings was feasible and rewarding for all partners and members.

There are also implications for future studies. For example, more knowledge is needed to understand what are the most effective recruitment/retention strategies across different types of settings, particularly those in the most underserved areas with limited access to community resources and/or eye care. As Mwachofi and WaMwachofi (2008) recommend, it is also important for regular surveillance of research structures in order to guide allocation of resources for health research as well as programs. Other studies using qualitative research are needed to further examine the reasons for participating/not participating in health promotion studies. Along similar lines, entry and exit surveys among African American participants who enroll in clinical research should be conducted to elucidate the reasons behind decision-making and/or stay or not stay in studies would be informative.

The main limitation of this study was that we did not contact center staff to see if we could identify ways to contact participants we could not reach for telephone follow-up. The reason being was that as this was our initial step in developing partnerships, we did not want to overburden staff and risk centers withdrawing cooperation. Also, we had to keep in mind

that our partners had different perspectives on the importance of the research versus service. We were cognizant of the fact that even when we were given permission to conduct research in the agencies, we were “visitors”. To strengthen our relationship, it was important to engage in active participation, listening, and responding to the needs of our partners versus focusing on any limitations. In doing so, we found that it helped to enhance our credibility which ultimately resulted in successful recruitment/retention of a large sample of older African Americans. Also, while we utilized several community agencies across urban and rural areas of the Deep South, these agencies were representative of one organization (AOA). Thus, we may have missed those African Americans who are the most underserved and do not have access to such agencies. This is another area for future research.

Several future efforts to improve representation of minority health populations are noteworthy. Standardization of terminology used and definitions may better help to understand the effectiveness of different strategies to enhance recruitment and retention (i.e., enrollee, attrition, loss to follow-up, refusal, accrual, contact failure). Many of these terms have been used differently across studies or were not clearly defined (Yancey, Ortega, & Kumanyika, 2006). Similar to our approach, active efforts for successful engagement in studies may be enhanced by flexibility in intervention protocols, minimal staff turnover, fostering of connections with staff and/or participant family and friends to minimize loss to follow-up, strategies to decrease participant burden (i.e., highly trained staff to efficiently administer questionnaires, study protocols), communication regarding research participation by medical providers, recruitment goals, continued connections with the community post-research to foster recruitment for future projects and/or trust and interest in research. Other more distal engagement strategies may include dissemination of information in the target population and within the population’s community (i.e., public service announcements, flyers, advertisements, podcasts, media relations, church leaders) designed to prompt prospective participants to contact project staff regarding involvement in ongoing studies.

## CONCLUSION

Utilizing a strategic plan that addresses the systematic development of collaborative, community partnerships and also accounts for plans for to solve potential problems has great promise toward improving underrepresentation of minorities in clinical research.

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**Table 1****Strategic Plan for Recruitment.**

<b>Objective 1: Generate a List of Potential Community Agencies</b>	
<ul style="list-style-type: none"> <li>We identified a list of possible senior centers in specific regions of the state where African Americans represented a significant percentage of the general population</li> <li>In an effort to evaluate the impact of the community-based program on older African Americans from different socioeconomic statuses, centers in both urban and rural locations were identified through contact with the Area Agencies on Aging (AOA) in Montgomery and Birmingham, Alabama and in the rural Black Belt region of Alabama in the central part of the state</li> </ul>	
<b>Objective 2: Establish Community Agency Partnerships</b>	
<ul style="list-style-type: none"> <li>The principal investigator and study coordinator met initially with the administrators from the area AOA to discuss the project</li> <li>An emphasis was placed on the disparity in eye health care for older African Americans, how our project could ultimately help address this problem, and the potential impact of the research on their community members</li> <li>This meeting helped to             <ul style="list-style-type: none"> <li>Highlight the significance of the problem among African Americans</li> <li>Provide a potential solution</li> </ul> </li> <li>Center directors had the opportunity to provide feedback and offer suggestions based on their catchment area</li> <li>This was an open dialogue for learning from each other in terms of the feasibility and benefits of the project and how the study is consistent with their agency's mission</li> <li>Individual centers were contacted to determine whether they were interested in hosting the InCHARGE© project in their center</li> <li>All centers that were contacted, welcomed talking to us further about the program, and thus face-to-face meetings were set up between the project coordinator and center's director</li> <li>The intent of the initial meeting was to learn about the center, its programs, tasks and demands on staff, and the demographics and service needs of the community, and to establish how our program might fit into the overall mission. We emphasized that our goal was to fit into the day-to-day workings of the center, and thus not be an inconvenience to ongoing programs. This also allowed our project coordinator the opportunity to elicit administrator feedback about feasibility, potential strategies to enhance recruitment/retention, potential obstacles, protocol administration in light of center and staff schedules, and to understand the cultural factors impacting the research project.</li> <li>While this was the initial step in establishing trust and an alliance, this encounter was followed up by ongoing telephone conversations.</li> <li>Altogether 23 centers were approached. While all 23 were interested in hosting our program, only 3 were unable to participate because of scheduling conflicts or due to ongoing renovations in the center during the study time period.</li> </ul>	
<b>Objective 3: Protocol Training/Administration</b>	
<ul style="list-style-type: none"> <li>All members of the project team met to communicate about the feedback from the site meetings in relation to the study aims, project protocol, delivery of program content, administration of outcome measures, and issues surrounding recruitment and retention strategies</li> <li>Cultural issues were also discussed that were identified from our initial focus groups and during our discussions with center staff and community members</li> <li>The project coordinator then visited each of the centers one last time before the program date so that all relevant persons were informed about the project flow and logistics prior to implementation</li> <li>We continued to build trust from our initial conversations with administrators and staff by openly describing our rationale for our procedures (i.e., tape recording programs, study measures)</li> <li>We described the proposed protocol and rationale for the study along with how the project could ultimately help their community members</li> <li>Providing a purpose and rationale is critical, especially when working in centers not used to research</li> </ul>	
<b>Objective 4: Plans for Successful Recruitment and Continued Building of Community Agency Partnerships</b>	
<ul style="list-style-type: none"> <li>Project staff and center leaders discussed possible barriers to recruitment and retention:             <ul style="list-style-type: none"> <li>Historical mistrust of researchers/outsideers</li> <li>Previous experiences with healthcare providers</li> </ul> </li> </ul>	

- Lack of culturally relevant study materials
  - Socioeconomic and demographic factors (e.g., lack of access to a telephone for follow-up calls; lack of insurance or access to healthcare)
  - Relocating
  - Health beliefs/attitudes
  - Health literacy
  - Hesitancy to participate after seeing necessary form to be signed (e.g., informed consent form that can appear similar to a legal document)
  - Poor, previous experiences in research or healthcare
  - Lack of interest
  - Discomfort with randomization
  - Avoidance/fear of eye care
- A plan was put in place that outlined recruitment strategies, set goals, and included ongoing contact with center staff. We were flexible to feedback and made necessary adjustments to the study design. We also conducted the study at the senior centers to minimize costs and inconvenience to participants.
  - Recruitment strategies included several advertisements (brochures for staff to handout, posters)
  - *Community Atmosphere:* Center personnel create an atmosphere and attitude about research at the agency prior to and in between data collection or program delivery that can encourage or discourage participant recruitment and retention. We recognized that it is the agency staff that community members trust and have relationships with. They are coming to community centers for services and social contact, not explicitly to be a part of a research study. If the atmosphere of the community agency or center is supportive of the research project and agency staff are convinced of the rationale and ultimate goal of the research, then community members will likely sense this attitude and be far more likely to participate. This information can be transmitted through a printed flyer or verbal message from the receptionist.



**Table 2**

Strategic Plan for Retention with Community Agencies/Centers.

<b>Objective 1: Ongoing Contact</b>
<ul style="list-style-type: none"> <li>The importance of successful retention requires the researchers' presence and involvement with the members. Thus, retention efforts centered on several strategies: <ul style="list-style-type: none"> <li>Disseminating our contact information (name, phone number, address) to community agency staff and participants</li> <li>Continuing to build trust through ongoing contact with participating community centers</li> <li>Keeping centers aware of any changes in project staff or protocol adjustments</li> <li>Conducting persistent phone calls to participants</li> <li>Having flexibility in terms of scheduling and/or rescheduling missed calls</li> <li>Mailing out reminder letters to hard to reach participants</li> <li>Using the same interviewer over time who also conducted the program (familiar voice)</li> <li>Making information easy to find (e.g., resource booklet of eye health providers/curriculum and placed in a tote bag that was provided to each participant and had our contact information)</li> </ul> </li> </ul>
<b>Objective 2: Availability of Easy to Locate Research Contact Information</b>
<ul style="list-style-type: none"> <li>We also informed participants that our contact information was located in their program materials and provided them with instructions for how to contact project staff in case of any questions</li> </ul>
<b>Objective 3: Letters/Cards</b>
<ul style="list-style-type: none"> <li>We sent out letters to participants we could not reach by telephone and also sent holiday/birthday cards to participants</li> <li>Upon completion, we also sent thank you cards to each of the centers to show our appreciation for their continued support and participation</li> </ul>
<b>Objective 4: Feedback to Community Participants &amp; Partners</b>
<ul style="list-style-type: none"> <li>We informed participants and centers that once the study was complete, we would be sharing the information that was learned with them</li> </ul>
<b>Objective 5: Consistency in Staff</b>
<ul style="list-style-type: none"> <li>We used the same interviewer over time who was also at the center on the day of the program as well (i.e., a familiar person and voice). This person made herself accessible post-program by providing her name and phone number to the participant.</li> </ul>

**Table 3**

Recruitment/Retention Characteristics for the Pooled Studies.

Characteristics	Total <sup>a</sup> (N = 380)	3-month follow-up <sup>b</sup> (N = 197)	6-month follow-up <sup>c</sup> (N = 183)
<b>Participants who Completed Follow-Up</b>	n = 264	n = 147	n = 117
% Retention rate (based on eligibility criteria)	71%	75%	66%
Age, <i>M(SD)</i>	75.62 (8.28)	75.35 (8.19)	75.97 (8.43)
Gender, <i>n(%)</i>			
Women	220 (83%)	118 (80%)	102 (87%)
Men	44 (17%)	29 (20%)	15 (13%)
Average # of telephone attempts until follow-up completed, <i>M(SD)</i> & range	2.08 (1.90), 1–14	2.29 (2.20), 1–14	1.81 (1.40), 1–7
<b>Participants Who Did Not Complete Follow-Up</b>	n = 116	n = 50	n = 66
% Loss to Follow-Up	29%	25%	34%
Age, <i>M(SD)</i>	75.44 (11.28)	7.02 (10.41)	75.76 (11.98)
Gender, <i>n(%)</i>			
Women	84 (72%)	31 (62%)	53 (80%)
Men	32 (28%)	19 (38%)	13 (20%)
Reasons for incompleteness, <i>n(%)</i>			
Invalid or Disconnected Telephone Number	38 (33%)	15 (30%)	23 (35%)
Busy signal	1 (1%)	1 (1%)	0
Left message	4 (3.5%)	1 (2%)	3 (4%)
No Answer	16 (14%)	5 (10%)	11 (17%)
Deceased	3 (2.5%)	3 (7%)	0
Severe Cognitive Impairment	21 (18%)	8 (16%)	12 (18%)
Refused	15 (13%)	10 (20%)	5 (8%)
Other (ineligibility criteria or undetermined reasons)	18 (17%)	7 (14%)	12 (18%)

Note.

<sup>a</sup> = pooled data from all three studies;<sup>b</sup> = data from the first two feasibility studies;<sup>c</sup> = data from the randomized clinical trial.

**Table 4**  
Recruitment and Retention Characteristics for Rural and Urban Participants from the Pooled Studies.

Characteristics	Total Sample <sup>a</sup> (N = 380)		3-month follow-up <sup>b</sup>		6-month follow-up <sup>c</sup>	
	Rural (n = 112)	Urban (n = 268)	Rural (n = 112)	Urban (n = 85)	Urban only (n = 183)	
<b>Participants Who Completed Follow-Up (n = 264)</b>						
% Retention rate (based on eligibility criteria)	n = 75	n = 189	n = 75	n = 72	n = 117	
Age, <i>M(SD)</i>	71%	72%	71%	85%	66%	
Gender, <i>n</i> (%)	74.34 (10.12)	76.34 (8.45)	73.85 (7.64)	76.93 (1.02)	75.76 (11.98)	
Women	61 (81%)	159 (84%)	61 (81%)	57 (79%)	102 (87%)	
Men	14 (19%)	30 (16%)	14 (19%)	15 (21%)	15 (13%)	
Average # of telephone attempts until follow-up complete, <i>M(SD)</i> & range	2.32 (2.4), 1–14	1.98 (1.65), 1–10	2.32 (2.40), 1–14	2.27 (1.99), 1–10	1.81 (1.40), 1–7	
<b>Participants Who Did Not Complete Follow-Up (n = 116)</b>						
Age, <i>M(SD)</i>	n = 37	n = 79	n = 37	n = 13	n = 66	
Gender, <i>n</i> (%)	74.34 (10.12)	75.96 (11.82)	74.34 (10.12)	77.00 (11.43)	75.76 (11.98)	
Women	21 (57%)	63 (80%)	21 (57%)	10 (77%)	53 (80%)	
Men	16 (43%)	16 (20%)	16 (43%)	3 (23%)	13 (20%)	
Reasons for incompletion, <i>n</i> (%)						
Invalid or disconnected telephone number	14 (38%)	24 (30%)	14 (38%)	1 (8%)	23 (35%)	
Busy signal	0	1 (1%)	0	1 (8%)	0	
Left message	0	3 (3%)	0	0	3 (4%)	
No answer	3 (8%)	13 (17%)	3 (8%)	2 (15%)	11 (17%)	
Deceased	3 (8%)	0	3 (8%)	0	0	
Severe cognitive impairment	9 (24%)	12 (15%)	9 (25%)	0	12 (18%)	
Refused	2 (6%)	13 (17%)	2 (5%)	8 (61%)	5 (8%)	
Other (ineligibility criteria or undetermined reasons)	6 (16%)	13 (17%)	6 (16%)	1 (8%)	12 (18%)	