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# Review Strategies to Recruit and Retain Rural Patient Participating Self-management Behavioral Trials

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## Review Strategies to Recruit and Retain Rural Patient Participating Self-management Behavioral Trials

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#### Abstract

Self-management plays a vital role in improving health outcomes and reducing costs in patients with cardiovascular disease (CVD) and associated risk factors. Based on existing studies, rural residents with CVD and/or risk factors show low engagement in self-management behaviors. Due to low participation in behavioral intervention trials, the most promising mechanism to promote self-management among rural populations is unknown. In turn, the purpose of this article is to review the evidence that supports strategies to recruit and retain rural patients to participate in behavioral intervention trials aimed to promote self-management of CVD and its risk factors. This review is expected to assist researchers in identifying effective solutions to overcome barriers in the recruitment and retention processes when conducting intervention research studies on the self-management of CVD in rural communities.

#### Background

In rural communities, the prevalence of CVD is 13.1%, compared to 11.2% in urban communities (Health Data Interactive, 2014; National Center for Health Statistics, 2012). This increased rate leads to disproportionate care burdens among individuals and healthcare service providers in rural areas (Cosby et al., 2008; P. Reddy et al., 2002). Moreover, the average age of the rural population continues to increase, along with the proportion of older persons living with CVD and other comorbidities (Dibartolo & McCrone, 2003; Health Data Interactive, 2014; National Center for Health Statistics, 2012). One primary approach to treat CVD and its risk

factors is to promote self-management behaviors (<u>Gillies et al., 2007; P. Reddy et al., 2011</u>). However, individuals in rural areas living with CVD and risk factors of CVD (e.g., hypertension, hyperlipidemia, diabetes, obesity, sedentary lifestyles, and unhealthy diets) often show low engagement in self-management behaviors (<u>P. Reddy et al., 2011</u>). Furthermore, compared to the research participation rate in urban residents (19.3%), rural residents had a lower research participation rate (8.7% for less remote and 13.6% for highly remote rural areas) (<u>Baquet, Commiskey, Daniel Mullins, & Mishra, 2006; Bergeron et al., 2013</u>). An adequate sample size of rural participants is needed to identify feasible and effective interventions to promote self-management behaviors and improve the cardiovascular health of individuals in rural areas (<u>Bergeron et al., 2013; Ford et al., 2008; Sateren et al., 2002</u>). A low participation rate impedes conducting a high quality study with adequate statistical power and generating valid evidence (<u>Baquet et al., 2006; Bergeron et al., 2013</u>). Therefore, the purpose of this review is to improve research participation by examining strategies to recruit and retain rural patients with CVD or its risk factors to participate in behavioral intervention trials intended to promote self-management behaviors.

To identify articles reporting recruitment and retention strategies in conducting self-management intervention trials in rural settings, we searched electronic databases, including the Cumulative Index of Nursing and Allied Health Literature (CINAHL), Embase (EMBASE and MEDLINE from 1974 forward), PubMed (PREMEDLINE, MEDLINE, etc.), and the Cochrane library. The following keywords were used alone or in combination: "enrollment," "recruitment," "retention," "barrier," "obstacle," "impediment," "attrition," "patient dropouts," "selfmanagement," "behavior" or "behavioral," "rural," "cardiovascular disease risk," "heart disease risk," and "clinical trials." The citation retrieval and screening process was conducted independently by two authors using the following inclusion and exclusion criteria. Studies were included if 1) they were published in English; 2) they were published from 1978 to September 30, 2014 (i.e., search end date); 3) study participants lived in a rural area and had CVD or risks factors of CVD; 4) the original study was a randomized control trial; 5) the trial examined the effects of behavioral change intervention on CVD risk reduction; 6) the intervention(s) targeted individuals, communities, settings, groups or whole populations in rural areas; 7) the study reported recruitment strategies or 8) the descriptive studies/reviews examined the strategies to participate interventional studies in rural areas. Studies were excluded if 1) the participants were younger than 21 years of age; 2) the study examined the effects of a behavioral change intervention on mental health-related symptom outcomes only (e.g., depression, anxiety); 3) the target population was minority-specific or cultural specific, but not for rural populations; 4) the target population had pregnancy and/or birth-related cardiac conditions; 5) the study did not have the complete text available; and 6) the study did not address strategies to enhance participation of behavior intervention trials.

Among 5,027 articles initially retrieved from the keyword search, 1,026 articles were selected for title screening. 921 articles were excluded because of irrelevant target populations or missing abstracts. Among 105 articles included for abstract appraisal, 35 articles and their reference lists were examined for eligibility. A final sample of 15 articles were included in this review. The results of the search were managed in a web-based bibliography and database manager (RefWorks, ProQuest LLC, Baltimore, MD).

#### Results

#### Study and Participant Characteristics

The selected studies were conducted in three countries: the United States (Befort, Bennett, Christifano, Klemp, & Krebill, 2014; Bergeron et al., 2013; Dibartolo & McCrone, 2003; Miyamoto, Henderson, Young, Ward, & Santillan, 2013; Parra-Medina et al., 2004; Pribulick, Willams, & Fahs, 2010; Tanner, Kim, Friedman, Foster, & Bergeron, 2014) Canada (Taylor, Stone, & Huijbregts, 2012), and Australia (P. Reddy et al., 2011). The sample sizes of the studies ranged from 119 to 530 participants (Befort et al., 2014; Bergeron et al., 2013; Dibartolo & McCrone, 2003; Miyamoto et al., 2013; Parra-Medina et al., 2004; Pribulick et al., 2010; P. Reddy et al., 2011; Tanner et al., 2014; Taylor et al., 2012). Among the included studies (Befort et al., 2014; Befort et al., 2014; Bergeron et al., 2013; Miyamoto et al., 2013; Parra-Medina et al., 2004; Pribulick et al., 2010; P. Reddy et al., 2011; Tanner et al., 2014; Taylor et al., 2012), the mean age of participants was 59.5 years, ranging from 35 to 84 years. Among all studies (Befort et al., 2014; Bergeron et al., 2013; Dibartolo & McCrone, 2003; Miyamoto et al., 2013; Parra-Medina et al., 2004; Pribulick et al., 2010; P. Reddy et al., 2011; Tanner et al., 2014; Taylor et al., 2012), 64% of the participants were female. For studies that reported the race/ethnicity of participants (Befort et al., 2014; Parra-Medina et al., 2004; Pribulick et al., 2010; Tanner et al., 2014; Taylor et al., 2012), 88% of the participants were White/Caucasian.

#### **Recruitment and Retention Process**

Locations for recruitment included both non-healthcare settings (Bergeron et al., 2013; Pribulick et al., 2010; Tanner et al., 2014; Taylor et al., 2012) and healthcare settings (Befort et al., 2014; Dibartolo & McCrone, 2003; Miyamoto et al., 2013; Parra-Medina et al., 2004; P. Reddy et al., 2011). Two commonly used recruitment approaches were specific and nonspecific targeting. The first approach involved direct targeting of potential candidates by face-to-face interviews (Miyamoto et al., 2013; Taylor et al., 2012), phone contact (Befort et al., 2014; Miyamoto et al., 2013), and referrals by healthcare professionals (Befort et al., 2014; Miyamoto et al., 2013; P. Reddy et al., 2011). The second approach involved nonspecific recruitment methods, such as study posters and brochures (Befort et al., 2014; Dibartolo & McCrone, 2003; P. Reddy et al., 2011), media and newspaper advertisements (Befort et al., 2014; Miyamoto et al., 2013; P. Reddy et al., 2011) public service announcements on radio and television stations (Dibartolo & McCrone, 2003; P. Reddy et al., 2011), word of mouth (Dibartolo & McCrone, 2003), and mass mailings (Befort et al., 2014; Miyamoto et al., 2013). Studies by Befort et al. (2014) and Miyamoto et al. (2013) reported that mass mailing with a personalized cover letter from providers reached the largest proportion of potential participants, followed by direct provider referrals, phone contact, and media advertisements. However, the most successful recruitment method is direct referral by healthcare providers (Befort et al., 2014; Miyamoto et al., 2013; P. Reddy et al., 2011), followed by participant referral/word of mouth, media advertisements, study brochures, presentations (P. Reddy et al., 2011). Befort et al. (2014) and Dibartolo and McCrone (2003) reported the direct mailing as well as media advertising contributed to the lowest enrollment rate (25.4% and 23.1%), while the direct provider referral accounted for the highest enrollment rate (48.4%) followed by phone contact (33.7%).

To organize the reported strategies, we used four categories: 1) strategies to enhance community engagement with clinical research; 2) strategies to improve the research process; 3) strategies to improve patient's participations; and 4) strategies to improve access to research (Figure 1).

Figure 1. Strategies to Recruit and Retain Rural Patient Participating in Self-management Behavioral Trials

Community	<ul> <li>Community engagement</li> <li>Community assessment</li> </ul>
Research Process	<ul> <li>Raise awareness, knowledge and understanding</li> <li>Local recruiter</li> <li>Training</li> <li>Provider referrals</li> </ul>
Patient Participation	<ul> <li>Social support</li> <li>Establish trust</li> <li>Emphasize "productivity" and "independence"</li> <li>Achieve greater good</li> </ul>
Access to Research	<ul> <li>Transportation</li> <li>Telehealth-delivered intervention</li> </ul>

## 1. Strategies to Enhance Community Engagement with Clinical Trial

## Enhance community engagement

Studies showed that strategies to enhance the community engagement were effective in raising community awareness and knowledge of clinical research (Miyamoto et al., 2013), leading to improved recruitment and retention rates (Melvin et al., 2013). Melvin et al. (2013) and other researchers (Miyamoto et al., 2013; P. Reddy et al., 2011) reported that the following approaches harness community engagement: (1) training and involving local investigators, lay-person(s) and/or group support; (2) developing multi-level intervention that targets both individuals and the community as a whole; (3) involving local organizations such as primary care clinics, hospitals, churches, grocery stores, schools, and worksites; (4) increasing public awareness of the research project by presenting at local community events (e.g., health fairs) and local organizations and small business (e.g., factories); and (5) funding local clinics for research studies. Furthermore, other studies (Melvin et al., 2013; Pribulick et al., 2010; P. Reddy et al., 2011) demonstrated the most effective strategy in response to the lack of research infrastructure in rural communities is the development community-academic-funder partnerships in which investigators obtain support from community leaders, government agencies (e.g., Health and Human Services departments), as well as potential funders (e.g., federal or private insurance programs) (Pribulick et al., 2010; P. Reddy et al., 2011). The Community-Based Participatory Research (Minkler & Wallerstein, 2010; Viswanathan et al., 2004) and the Practice-Based Research Networks (Lindbloom, Ewigman, & Hickner, 2004; Mold & Peterson, 2005) are two

models reported to guide the development of long-term partnerships with rural communities. The Community-Based Participatory Research model involves community members in the research study in order to enhance trust, determine rural health concerns, identify local resources, and match and sustain long-term collaborations with community members where a potential pool of participants is located (Minkler & Wallerstein, 2010; Viswanathan et al., 2004). The Practice-Based Research Networks model (Lindbloom et al., 2004; Mold & Peterson, 2005), on the other hand, utilizes rural healthcare providers to conduct research (Green & Hickner, 2006). Sustained partnerships can enhance the efficiency of funding utilization, maximize community resources, facilitate training of local investigators, and generate alternative strategies for unexpected research occurrences, leading to future research endeavors (Melvin et al., 2013; Miyamoto et al., 2013).

## Conduct community assessment

In addition to building infrastructure and partnerships, it is also advisable that a comprehensive community needs assessment be conducted prior to implementing a research program (Tanner et al., 2014). Such an assessment enables investigators to properly identify the diverse cultural and social traits within each community (Tanner et al., 2014). The specific needs collected from this assessment can be used to create tailored communication strategies (Tanner et al., 2014). Further, the community needs assessment helps to identify existing healthcare services and avoid duplication (Miyamoto et al., 2013). Several studies suggested life-long behavioral changes can be accomplished by integrating research programs with local health promotion services and utilizing community existing resources to deliver interventions (Pribulick et al., 2010; P. Reddy et al., 2011).

## 2. Strategies to Improve the Research Process

## Raise research awareness, knowledge and understanding

To improve the participation rate of rural residents, extra time and effort should be devoted to raising awareness of the study, helping potential participants understand complex research documents, and describing the risks, benefits, costs and time commitment required for participation in the study (Dibartolo & McCrone, 2003). It is advised that plain language should be used when providing research information and explaining consent (Bergeron et al., 2013; Miyamoto et al., 2013; Tanner et al., 2014). Specifically, study materials should be written at a fifth-grade reading level and translated as appropriate for speakers of minority languages (Miyamoto et al., 2013). Assistance should be available to help participants fill out forms and additional information should be readily available on request (Miyamoto et al., 2013; Tanner et al., 2013) reported that one of the most common reasons for participating in their study was the desire to improve knowledge and understanding to help control the disease in question.

## Utilize local recruiter

To meet ethical regulation requirements and increase the participation rate, we recommend the use of local recruiters who have legal access to patients' information (Kulynych & Korn, 2003). Local recruiters residing in the community often have established relationships with the participants and their care provider (Dibartolo & McCrone, 2003; Miyamoto et al., 2013; Parra-

<u>Medina et al., 2004; Pribulick et al., 2010; P. Reddy et al., 2011; Tanner et al., 2014</u>). Therefore, they are able to better communicate with potential participants using language appropriate to their community's culture (<u>Miyamoto et al., 2013</u>).

## Provide training

To improve urban researchers' understanding of rural culture and values, mandatory training is recommended to increase knowledge, skills, and cultural competency with respect to recruiting rural residents (Tanner et al., 2014). Pribulick et al. (2010) further contended that, prior to conducting a study, researchers be made aware of their own biases and prejudices regarding rural residents' perceptions of clinical trials.

## Encourage provider referrals

Physician referrals are one of the most effective ways to recruit rural patients for clinical trials (Befort et al., 2014; Miyamoto et al., 2013; P. Reddy et al., 2011; Tanner et al., 2014). Rural healthcare providers are more likely to refer their patients to clinical trials if they are aware of and understand the methods involved (Comis, Miller, Aldige, Krebs, & Stoval, 2003). However, findings by Tanner et al. (2014) suggest that rural healthcare providers lack awareness and knowledge of ongoing clinical trials. Therefore, it is highly encouraged that research investigators devote time and resources to identifying effective ways of communicating about medical research with local healthcare providers (Tanner et al., 2014). Moreover, it is recommended that researchers develop positive relationships with rural health care providers prior to initiating a study (Miyamoto et al., 2013; P. Reddy et al., 2011). The ongoing communication during clinical trials is also critical to reinforce the commitment of rural healthcare providers to the study (Miyamoto et al., 2013; Pribulick et al., 2010; P. Reddy et al., 2011). In addition, it is important that local providers and their teams (e.g., clinical managers, office staff, nurses) be adequately informed of the purpose, intervention mechanism, outcomes, and potential risks and benefits of the trial (Miyamoto et al., 2013; Pribulick et al., 2010; P. Reddy et al., 2011).

Approaches to actively engage local providers in research studies include utilizing rural clinics for research-related activities such as interviews, local laboratory testing, and intervention administration (Miyamoto et al., 2013). Additionally, such approaches involve providing training and support to communicate project goals and benefits to participants (Miyamoto et al., 2013). However, the investigators must take into consideration that due to limited capacity and constraints in time and resources, rural provider teams also have more limited commitment and involvement. Likewise, considering the balance between daily clinical operations and research-related tasks, added care should be taken to prevent participating providers from feeling overwhelmed or burdened by the study (Miyamoto et al., 2013).

## 3. Strategies to Improve Patient Participation

## Provide social support

Peer and family support play vital roles in the participation of rural individuals in clinical trials (Dibartolo & McCrone, 2003; Taylor et al., 2012). In turn, studies suggest that researchers personally discuss information regarding the risks and benefits of the study through an initial face-to-face meeting with both the potential participants and their family member(s) (Taylor et

al., 2012). Studies recommend identifying the peer support for the potential participants through community-based formal and informal organizations such as church groups, bible study groups, or others (Dibartolo & McCrone, 2003). To increase the recruitment and retention rate, it is imperative that the research teams work collaboratively with group leaders, organization coordinators, and volunteers to mobilize the participants' support systems (e.g. children, spouse, neighbors and friends) (Taylor et al., 2012). Furthermore, research teams provide valuable support to rural participants (P. Reddy et al., 2011). Reddy et al. (2011) reported that participants appreciated timely and positive feedback about the effectiveness of the intervention during the study, which was one of the factors that encouraged them to continue in the study. Ongoing monitoring and feedback have been reported to be effective at enhancing retention of participants (Pribulick et al., 2010). This feedback provides the support and confidence needed to actualize a behavioral change (Pribulick et al., 2010). Regular monitoring can be completed by sending reminder letters, greeting cards (e.g., three-, and twelve-month anniversary and birthday cards), calling to discuss test reports, and/or follow-up calls (Befort et al., 2014; Miyamoto et al., 2013; P. Reddy et al., 2011).

#### Establish trust

Establishing trust between rural residents and the research team is vital to increasing enrollment and retention rates (Dibartolo & McCrone, 2003). Long and Weinert (1989) found that rural individuals distrust "outsiders," healthcare systems, and government agencies (Dibartolo & McCrone, 2003; Pribulick et al., 2010). They are reluctant to accept help and services from "outsiders" or "government agents" and instead rely on their family, neighbors, and friends for healthcare needs and information, which affects their willingness to participate in clinical trials conducted by "outsiders" (Dibartolo & McCrone, 2003; Long & Weinert, 1989). One effective way to build rapport is through initial, in-person meetings with each potential participant (Taylor et al., 2012). During these meetings, researchers are able to identify beliefs, perceptions, and attitudes of participants towards healthcare and research (P. Reddy et al., 2011). With this knowledge, researchers can then engage in a tailored discussion that explicitly describes the potential risks and benefits of the study in order to clarify misperceptions and/or unfavorable attitudes (P. Reddy et al., 2011). Another effective way to modify attitudes and beliefs of rural individuals regarding clinical trials is to provide free risk screenings (P. Reddy et al., 2011). Not only do such free services raise awareness of research programs, but they also provide an alternant and complement to primary care in rural communities where preventive healthcare service often is lacking (P. Reddy et al., 2011).

#### Emphasize productivity and independence as health outcomes

The cultural perspective and values of rural residents are unique from their urban counterparts (Long & Weinert, 1989). Long and Weinert found rural residents generally believe that health is attained through work, from being productive and by functioning as usual (Long & Weinert, 1989). Likewise, work needs are often put above health needs (Long & Weinert, 1989). Long and Weinert also found that rural individuals tend to desire independence and self-sufficiency (Dibartolo & McCrone, 2003; Long & Weinert, 1989). The perception of health and health practice have an impact on their participation in clinical trials (Dibartolo & McCrone, 2003; Tanner et al., 2014). Incorporating independence and productivity or their correlates (e.g. functioning) as study outcomes will help the rural residents understand the study benefits and motivate them to enroll.

## Emphasize the greater good

Many rural residents expressed altruistic motives based on their religious faith, as well as the opportunity to help others and give to society (<u>Dibartolo & McCrone, 2003</u>). A rural individual is more likely to participate if she or he perceives the benefit of participation either as a personal gain or as a contribution to research, society, and the greater good (<u>Dibartolo & McCrone, 2003</u>; <u>Miyamoto et al., 2013</u>). Therefore, it is important to inform rural participants that their participation in the study benefits others and overall healthcare.

## 4. Strategies to Improve Access to Research

## Provide transportation or alternatives

To overcome barriers resulting from lack of transportation for rural participants, some investigators offered reimbursement (Befort et al., 2014; Miyamoto et al., 2013; Parra-Medina et al., 2004; Pribulick et al., 2010; P. Reddy et al., 2011; Taylor et al., 2012) or free transportation (Miyamoto et al., 2013; Parra-Medina et al., 2004; Taylor et al., 2012) to alleviate their burden. Taylor et al. (2012) suggested utilizing telehealth devices as a safe and effective way of conducting rural clinical trials without necessitating long-distance travel. Notably, the participants their study did not report perceiving any difference in care by using telehealth as compared to face-to-face interviews (Taylor et al., 2012). As an additional means to improve recruitment and retention in rural communities. Taken together, perhaps a combination of these techniques would best help overcome barriers due to transportation and remote distances.

## Provide telehealth-delivered intervention and technology support

One potential route for rural intervention studies to minimize barriers to accessing clinical trials is by offering a telehealth-delivered intervention that can be completed at home (Miyamoto et al., 2013). In order to do so, adequate technology support should be available to participants. In several studies where on-site technical support was unavailable, participants perceived challenges and difficulty during both the intervention and data collection periods (Bergeron et al., 2013; Parra-Medina et al., 2004; Pribulick et al., 2010). Some investigators suggested obtaining extra funding and resources to provide technical support and on-site troubleshooting (P. Reddy et al., 2011; Taylor et al., 2012). Additional safeguards against technological difficulties could be to supply mobile devices to participants and have a contingency plan in place for phone calls rather than relying solely on video-conferencing (Taylor et al., 2012). Furthermore, to decrease technological issues, some studies provided participants with access to technical support through resources remotely provided by academic and urban settings (Bergeron et al., 2013). Community-academic-funder partnerships can also assist in building rural research infrastructure, which will ultimately benefit rural healthcare practices, improve the quality of care, and develop sustained support for technology (Cudney, Craig, Nichols, & Weinert, 2012; Miyamoto et al., 2013).

## Discussion

Recognizing rural residents' greater barriers to participate in research studies (Bergeron et al., 2013; Dibartolo & McCrone, 2003; Tanner et al., 2014), the purpose of this review is to

synthesize the most common strategies used to promote rural residents' enrollment in clinical trials aiming to enhance self-management behaviors. To overcome community-, research- and patient-related barriers, the investigators of the reviewed studies developed and implemented strategies to 1) promote community engagement with research; 2) improve the research process; 3) increase patients' desire to enroll in research projects and 4) improve access to research.

The efficiencies of recruitment and retention were reported in the reviewed studies (Befort et al., 2014; Dibartolo & McCrone, 2003; Miyamoto et al., 2013; Parra-Medina et al., 2004; Pribulick et al., 2010; P. Reddy et al., 2011). The mean recruitment rate (i.e., the number of potential participants willing to participate divided by the number of potential participants reached) was 15.5%, ranging from 11% to 21%. The mean enrollment rate (i.e., the number of participants enrolled divided by the number of potential and willing participants) was 39.5%, ranging from 29% to 47.6%. The mean retention rate (i.e., the number of participants who completed the study divided by the number of participants enrolled) was 75.5%, with a range of 70% to 81.5%.

None of these studies reported that one recruitment or retention strategy was more effective than another with a higher rate. Pribulick et al. (2010) suggested the use of multiple methods to facilitate rural recruitment and retention because the barriers to recruitment and retention were multilevel and multifaceted. The primary strategy to promote enrollment at the community level is to establish research infrastructure by developing community-academic-funder partnerships. To improve rural residents' participation rate, a research protocol must be modified to adapt to rural participants' needs and preferences. Among the strategies to increase participation at the patient level, provider referrals have a notably important role in motivating patients to participate in a clinical trial (Befort et al., 2014). More than 80% of participants requested his or her physician's opinion before consenting to participate in a study (Penman et al., 1984). Another frequently used patient-level strategy is to use local recruiters from the rural communities, such as staff and nurses working in rural health departments, clinics or hospitals, or volunteers (Befort et al., 2014; Befort et al., 2014; Bergeron et al., 2013; Dibartolo & McCrone, 2003; Miyamoto et al., 2013; Parra-Medina et al., 2004; Pribulick et al., 2010; P. Reddy et al., 2011; Tanner et al., 2014; Taylor et al., 2012). To enhance access to research, telehealth may be used to deliver interventions or conduct data collection. For studies where telehealth is not an option, intervention and data collection locations can be moved to local communities (e.g., workplaces, homes, clinics, health departments, community centers) (Pribulick et al., 2010). Local data collection sites improve retention by increasing the convenience for participants (Pribulick et al., 2010). To further increase access to clinical trials, investigators and their research teams can provide free diagnostic testing, health screening, and medical care as incentives to encourage participation (Bergeron et al., 2013; Pribulick et al., 2010).

## Limitations

We used strict criteria to guide our literature search and focus our review; therefore many articles were not discussed if they did not meet the search criteria. In addition, there are limited studies reporting on strategies in recruitment and retention for conducting self-management behavioral trials in rural areas. The number of articles included may be considered low. However, we used a systematic approach to locate appropriate articles, with the assistance of reference librarians and two research staff. The literature search process was intensive. Furthermore, each stage of the

search was performed independently by at least two research personnel to cross-validate the quality of studies. Therefore, the authors are confident that this review includes a comprehensive list of studies conducted in rural communities. Secondly, the generalizability and comprehensiveness of the review is also influenced by the selected studies which have their own limitations in terms of the heterogeneity of study design, quality of data collection and reporting, and rural population representativeness. Despite the limitations of the literature, this article is the first review of strategies in recruiting and retaining rural participants in clinical trials that promote self-management behaviors.

## Conclusions

The evidence regarding effective interventions to promote self-management behaviors in rural patients with CVD risks is lacking. Without strong and sufficient evidence, the development of effective programs and healthcare policies may not be achieved. Therefore, additional clinical trials with adequate sample sizes are needed to generate evidence to promote behavioral change. The reviewed strategies may potentially help investigators to improve recruitment and retention rates in rural communities.

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#### References

- Baquet, C. R., Commiskey, P., Daniel Mullins, C., & Mishra, S. I. (2006). Recruitment and participation in clinical trials: Socio-demographic, rural/urban, and health care access predictors. *Cancer Detection and Prevention*, *30*(1), 24-33. doi:S0361-090X(06)00003-1 [pii]
- Befort, C. A., Bennett, L., Christifano, D., Klemp, J. R., & Krebill, H. (2014). Effective recruitment of rural breast cancer survivors into a lifestyle intervention. *Psycho- Oncology*, doi:10.1002/pon.3614
- Befort, C. A., Klemp, J. R., Fabian, C., Perri, M. G., Sullivan, D. K., Schmitz, K. H., . . . Shireman, T. (2014). Protocol and recruitment results from a randomized controlled trial comparing group phonebased versus newsletter interventions for weight loss maintenance among rural breast cancer survivors. *Contemporary Clinical Trials*, 37(2), 261-271. doi:10.1016/j.cct.2014.01.010
- Bergeron, C., Foster, C., Friedman, D., Tanner, A., Kim, S., Friedman, Caroline Bergeron Caroline Foster Daniela, & Kim, A. T. S. (2013). Clinical trial recruitment in rural South Carolina: A comparison of investigators' perceptions and potential participant eligibility. *Rural and Remote Health*, 13(2567)
- Comis, R. L., Miller, J. D., Aldige, C. R., Krebs, L., & Stoval, E. (2003). Public attitudes toward participation in cancer clinical trials. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology, 21*(5), 830-835. doi:10.1200/JCO.2003.02.105

- Cosby, A. G., Neaves, T. T., Cossman, R. E., Cossman, J. S., James, W. L., Feierabend, N., . . . Farrigan, T. (2008). Preliminary evidence for an emerging nonmetropolitan mortality penalty in the united states. *American Journal of Public Health*, *98*(8), 1470-1472. doi:10.2105/AJPH.2007.123778 [doi]
- Cudney, S., Craig, C., Nichols, E., & Weinert, C. (2012). Barriers to recruiting an adequate sample in rural nursing research. *Online Journal of Rural Nursing and Health Care*, 4(2), 78-88.
- Dibartolo, M., & McCrone, S. (2003). Recruitment of rural community-dwelling older adults: Barriers, challenges, and strategies. *Aging & Mental Health*, 7(2), 75-82. doi:10.1080/1360786031000072295
- Ford, J. G., Howerton, M. W., Lai, G. Y., Gary, T. L., Bolen, S., Gibbons, M. C., . . . Bass, E. B. (2008). Barriers to recruiting underrepresented populations to cancer clinical trials: A systematic review. *Cancer*, 112(2), 228-242. doi:10.1002/cncr.23157 [doi]
- Gillies, C. L., Abrams, K. R., Lambert, P. C., Cooper, N. J., Sutton, A. J., Hsu, R. T., & Khunti, K. (2007). Pharmacological and lifestyle interventions to prevent or delay type 2 diabetes in people with impaired glucose tolerance: Systematic review and meta-analysis. *BMJ (Clinical Research Ed.)*, 334(7588), 299. doi:bmj.39063.689375.55 [pii]
- Green, L. A., & Hickner, J. (2006). A short history of primary care practice-based research networks: From concept to essential research laboratories. *Journal of the American Board of Family Medicine: JABFM*, *19*(1), 1-10. doi:19/1/1 [pii]

Health Data Interactive. (2014). Health data interactive. Retrieved from http://www.cdc.gov/nchs/hdi.htm

- Kulynych, J., & Korn, D. (2003). The new HIPAA (health insurance portability and accountability act of 1996) medical privacy rule: Help or hindrance for clinical research? *Circulation*, 108(8), 912-914. doi:10.1161/01.CIR.0000080642.35380.50 [doi]
- Lindbloom, E. J., Ewigman, B. G., & Hickner, J. M. (2004). Practice-based research networks: The laboratories of primary care research. *Medical Care*, 42(4 Suppl), III45-9. doi:00005650-200404001-00008 [pii]
- Long, K. A., & Weinert, C. (1989). Rural nursing: Developing the theory base. *Scholarly Inquiry for Nursing Practice, 3*(2), 113-127.
- Melvin, C. L., Corbie-Smith, G., Kumanyika, S. K., Pratt, C. A., Nelson, C., Walker, E. R., . . . Workshop Working Group on CVD Prevention in High-Risk Rural Communities. (2013). Developing a research agenda for cardiovascular disease prevention in high-risk rural communities. *American Journal of Public Health*, 103(6), 1011-1021. doi:10.2105/AJPH.2012.300984 [doi]
- Minkler, M., & Wallerstein, N. (2010). Community-based participatory research for health: From process to outcomes John Wiley & Sons.
- Miyamoto, S., Henderson, S., Young, H., Ward, D., & Santillan, V. (2013). Recruiting rural participants for a telehealth intervention on diabetes Self- Management. *The Journal of Rural Health*, 29(1), 69-77. doi:10.1111/j.1748-0361.2012.00443.x

- Mold, J. W., & Peterson, K. A. (2005). Primary care practice-based research networks: Working at the interface between research and quality improvement. *Annals of Family Medicine*, *3 Suppl 1*, S12-20. doi:3/suppl\_1/s12 [pii]
- National Center for Health Statistics. (2012). *Health, united states, 2011: With special feature on socioeconomic status and health.* Hyattsville (MD): doi:NBK54381 [bookaccession]
- Parra-Medina, D., D'antonio, A., Smith, S. M., Levin, S., Kirkner, G., Mayer-Davis, E., & POWER study. (2004). Successful recruitment and retention strategies for a randomized weight management trial for people with diabetes living in rural, medically underserved counties of South Carolina: The POWER study. *Journal of the American Dietetic Association*, 104(1), 70-75. doi:10.1016/j.jada.2003.10.014 [doi]
- Penman, D. T., Holland, J. C., Bahna, G. F., Morrow, G., Schmale, A. H., Derogatis, L. R., . . . Cherry, R. (1984). Informed consent for investigational chemotherapy: Patients' and physicians' perceptions. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, 2(7), 849-855.
- Pribulick, M., Willams, I. C., & Fahs, P. S. (2010). Strategies to reduce barriers to recruitment and participation. *Online Journal of Rural Nursing and Health Care: The Official Journal of the Rural Nurse Organization*, 10(1), 22-33.
- Reddy, P., Hernan, A. L., Vanderwood, K. K., Arave, D., Niebylski, M. L., Harwell, T. S., & Dunbar, J. A. (2011). Implementation of diabetes prevention programs in rural areas: Montana and south- eastern Australia compared. *Australian Journal of Rural Health*, 19(3), 125-134. doi:10.1111/j.1440-1584.2011.01197.x.
- Reddy, P., Dunn, A. B., White, C. M., Tsikouris, J. P., Giri, S., & Kluger, J. (2002). An economic analysis of amiodarone versus placebo for the prevention of atrial fibrillation after open heart surgery. *Pharmacotherapy*, 22(1), 75-80.
- Sateren, W. B., Trimble, E. L., Abrams, J., Brawley, O., Breen, N., Ford, L., . . . Christian, M. C. (2002). How sociodemographics, presence of oncology specialists, and hospital cancer programs affect accrual to cancer treatment trials. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology, 20*(8), 2109-2117. doi:10.1200/JCO.2002.08.056
- Tanner, A., Kim, S., Friedman, D. B., Foster, C., & Bergeron, C. D. (2014). Barriers to medical research participation as perceived by clinical trial investigators: Communicating with rural and African American communities. *Journal of Health Communication*, (ahead-of-print), 1-9. doi:10.1080/10810730.2014.908985
- Taylor, D., Stone, S., & Huijbregts, M. (2012). Remote participants' experiences with a group-based stroke self-management program using videoconference technology. *Rural Remote Health*, *12*, 1-15.
- Viswanathan, M., Ammerman, A., Eng, E., Garlehner, G., Lohr, K. N., Griffith, D., Lux, L. (2004). Community- based participatory research: Assessing the evidence: Summary. doi:NBK11852 [bookaccession]

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