



Published in final edited form as:

Contemp Clin Trials. 2013 May ; 35(1): 1–7. doi:10.1016/j.cct.2013.01.001.

Connecting Communities to Health Research: Development of the Project CONNECT Minority Research Registry

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Abstract

Introduction—Prevention and treatment standards are based on evidence obtained in behavioral and clinical research. However, racial and ethnic minorities remain relatively absent from the science that develops these standards. While investigators have successfully recruited participants for individual studies using tailored recruitment methods, these strategies require considerable time and resources. Research registries, typically developed around a disease or condition, serve as a promising model for a targeted recruitment method to increase minority participation in health research. This study assessed the tailored recruitment methods used to populate a health research registry targeting African-American community members.

Methods—We describe six recruitment methods applied between September 2004 and October 2008 to recruit members into a health research registry. Recruitment included direct (existing studies, public databases, community outreach) and indirect methods (radio, internet, and email) targeting the general population, local universities, and African American communities. We conducted retrospective analysis of the recruitment by method using descriptive statistics, frequencies, and chi-square statistics.

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Results—During the recruitment period, 608 individuals enrolled in the research registry. The majority of enrollees were African American, female, and in good health. Direct and indirect methods were identified as successful strategies for subgroups. Findings suggest significant associations between recruitment methods and age, presence of existing health condition, prior research participation, and motivation to join the registry.

Conclusions—A health research registry can be a successful tool to increase minority awareness of research opportunities. Multi-pronged recruitment approaches are needed to reach diverse subpopulations.

Keywords

diversity; recruitment; ethnic minorities; research registry; clinical trials

Introduction

Attention directed towards high-quality clinical and behavioral research is one mechanism to minimize disparities in disease and mortality [1]. Research studies that do not include diverse populations or are not conducted in real-world settings limit the generalizability and the relevance of the research results and may hinder translational efforts that could improve population health [2]. Since the NIH Revitalization Act's guidelines on the inclusion of minorities and women, a growing body of research has sought to understand influences on research participation among minority groups and test methods to recruit and enroll participants from populations most affected by the conditions studied [3-5].

Overwhelmingly the scientific literature describes factors that may be associated with *lack* of participation in research by minorities with only limited attention to factors that may *promote* research participation. In fact, there are numerous potential barriers to research participation that need to be considered. These barriers fall under the domains of provider interaction, study design, and healthcare system factors [6] and they are most commonly: distrust of the medical community or research [7-11]; perceived harms of research [12-14]; time and financial cost to the patient for participating [14]; and lack of awareness and opportunity to participate in research [6, 11].

In the limited scientific literature on factors that promote minority participation in research, participant awareness of the study and the opportunity to participate are the most salient influences. Ford and colleagues generated a model of clinical trials participation, which places awareness and opportunity as antecedents to decision making about research participation [6]. While this model is an important step toward identifying factors that positively influence research participation, further research on various methods to increase diverse participation in research remains needed.

Several targeted outreach strategies have shown promise to minimize barriers to participation in research studies and in turn improve recruitment of minorities into clinical and behavioral research [15, 16]. The following recruitment strategies, alone and in combination, have been demonstrated to be effective recruitment methods: mass media [17-20], print materials [16, 18, 21], and community outreach [17, 18, 22, 23]. Commonalities across the strategies are: intentional and proactive efforts to involve key leaders from the target population to plan the study; visible community presence; and providing the community with tangible resources or skills upon study completion [16, 20, 24]. Another commonality is that direct benefit is limited to the individual study or intervention for which the strategies were prompted. While identifying and implementing tailored recruitment strategies is critical and underdeveloped, intentional involvement of community leaders and other community based participatory research strategies are also

much needed areas for development with promise for reducing disparities in research participation.

Though less commonly used, population-based registries are also used for study recruitment and are most often used to recruit research study participants that share a common characteristic such as illness [25-37]. Less is known about the use of registries designed specifically to increase minority participation in research studies. In this paper we describe a registry developed to increase the participation of African Americans in research studies. We report on the recruitment strategies used in our study to identify potential registry members and the impact of those strategies.

Materials and Methods

Registry development

Project CONNECT was created as part of the Carolina-Shaw Partnership for the Elimination of Health Disparities (Project EXPORT) [38]. The guiding purpose of Project CONNECT is to establish trusting relationships with the Black community through community education of research participant protections and rights that will lead to meaningful participation in disparities research. Project CONNECT's registry and recruitment strategies were developed with guidance from consultants from the University of Alabama, the Project EXPORT Community Advisory Board (CAB), and the perspectives of local pastors on health research. University of Alabama consultants provided guidance on the registry infrastructure. The CAB and pastors identified various barriers to minority recruitment (described in more detail by Corbie-Smith and colleagues[39] and recommended strategies that address community concerns. They suggested a community kick-off for the registry, reviewed and approved registry consent forms, materials for health research outreach and orientation sessions, and the registry enrollment forms. Project CONNECT and all recruitment procedures received Institutional Review Board approval from The University of North Carolina at Chapel Hill (UNC).

Recruitment strategies

We conducted registry recruitment between April 2004 and October 2008. Inclusion criteria included self-identifying African Americans age 18 years or older. Individuals of other races were not excluded from enrolling in the registry, but were not targeted. Each enrollee provided informed consent and was asked for the following basic demographic information: age, race/ethnicity, gender, education level, organizational affiliation, history of research participation, how they heard about the registry, and health information, including chronic health problems and perceptions of general health. We contacted potential registry members using the following multi-pronged approach: 1) existing studies, 2) community outreach, 3) public databases, 4) radio, 5) email to university students and employees, and 6) internet recruitment through the registry website. New registry members received nominal incentives of pens, cups, and magnets embossed with the Project CONNECT logo. For each method, we calculated number of months spent on designated method (time period); number of individuals reached (reach); number of enrolled registry members (enrollment); research assistant activity contributed to travel, calls, emails, mailings, and related tasks to reach and enroll participants (staff hours); and additional costs tracked in budget reports such as radio fees and programmer time (additional costs). Staff hours documented activities of the project coordinator, research assistant, graduate student, and programmer. Ten individuals served these roles during the reporting period. Four additional staff employed by Shaw University's Center for Survey Research assisted with recruitment (as described under public databases). All but one staff member identified as African American. Two were male. No intentional effort was made to match staff to target audience by race, gender, or age.

All registry members received the Project CONNECT newsletter regardless of recruitment method. The newsletter served to increase awareness about research, update registry members of research studies, and share updates on current studies. We divided recruitment methods into direct and indirect methods. Direct methods were defined as methods that require direct contact with potential registry participants via phone or in person; for example, recruitment through contact with individuals identified through their participation in existing studies, direct community outreach, and public databases. Indirect methods included recruitment via the internet, email, and radio.

Direct recruitment methods

Existing studies—Between April and May 2004, we contacted via mail 500 individuals enrolled in a cancer epidemiologic study. Individuals received the following registry information: project brochure, postcard, and a letter signed by the study principal investigator referring individuals to the registry. Individuals who returned postcards agreeing to participate were enrolled in the registry. Project CONNECT staff made up to six follow-up phone calls to remaining individuals and enrolled those providing verbal consent.

Community outreach—Between May 2004 and October 2008, project staff conducted community outreach within rural and urban 22 communities located within 138 miles of UNC. During community presentations, orientation sessions, and other community health events, research team members distributed registry consent and enrollment forms and collected them from those desiring to enroll. Project CONNECT outreach efforts prioritized health fairs and conferences hosted at Black churches and community organizations as primary venues for registry recruitment. Before conducting presentations, research staff met with churches leaders to discuss the project. These early stage meetings typically led to additional meetings with health committees and other ministries within the same congregations. Presentations by the research staff were also conducted at some of the sites and focused on health topics disproportionately impacting African Americans (e.g. cancer, diabetes, and heart disease) in addition to information on research, patient protections, and the registry. All presentations concluded with invitations to enroll in the research participant registry. Informed consent was obtained on site from potential enrollees.

Public databases—The third direct recruitment method grew from a list sample provided by a commercial sampling company (Survey Sampling International, Shelton, CT). Between September and December 2004, Shaw University's Center for Survey Research (Shaw CSR) conducted telephone recruitment of individuals randomly selected from four NC counties. Eligible individuals received recruitment materials via mail to review and consider registry enrollment. Project staff conducted follow-up phone calls to assess interest in registry enrollment and enroll individuals.

Indirect recruitment methods

Radio—The first indirect recruitment strategy targeted radio listeners of Radio One's three regional radio stations (gospel urban, adult contemporary, and mainstream urban) spanning a six county metro-area (1.3 million population). During summer 2006, two alternating announcements aired for six weeks directing listeners to the registry's toll-free number. One announcement featured a brief role-play dialogue between two community members about types of research. The other followed a public service announcement format. Language in the announcement informed listeners that "*African Americans are heavily affected by chronic disease and poor health outcomes. Recent evidence shows that ethnic minorities are poorly represented in health research that could uncover ways to decrease high rates of illness. That's why Project CONNECT needs you. Project CONNECT, a part of the Carolina Shaw Partnership to Eliminate Health Disparities, is looking for volunteers to join*

a confidential registry. The Project helps people find people who may want to take part in future studies. Research may include surveys, interviews, workshops, or group discussions. Help improve our community's health and quality of life by contacting Project CONNECT at ..."

Email—From February 2005 through April 2008, the second indirect recruitment strategy was a mass email recruitment message. Email recipients included university students, faculty, and staff. The email message briefly described health disparities, the CONNECT registry, the various enrollment methods being used in the study (phone, email, and internet), and an invitation for recipients to enroll. The message clarified that registry enrollment was separate from enrollment into any specific research study. We used this strategy at both UNC (ten emails circulated quarterly from May 2008 through December 2009) and Shaw University (one message in 2006).

Internet—Electronic web enrollment was the final indirect recruitment strategy. This method allowed individuals who received print material, emails, or self-guided searches to self-enroll in the registry electronically. Usage statistics provided by the Webalizer, a web log analysis tool [40] calculated visits to the CONNECT website between August 2005 and October 2008.

Analysis

We calculated frequencies of the total number of study participants enrolled in the registry according to each 'direct' and 'indirect' method of recruitment. We used the chi-square statistic to test significance for paired crosstab associations. We also examined demographics, health conditions, and reasons that motivate individuals to participate according to the various recruitment methods. Frequencies and chi-square tests were conducted using SAS V9 [41]. Simple descriptive statistics described reach, staff person time, and costs across recruitment method.

Results

Sample characteristics

Table 1 presents the sample characteristics for the 608 registry participants. The majority of the registry participants were African-American, between the ages of 18 and 49, and female. Over one-third of the participants reported being married. Two-thirds reported favorable health status (good, very good, or excellent health). Seventeen percent of the sample reported having two or more medical conditions. The most common health condition reported by nearly a quarter of the sample was hypertension. The majority of the sample completed at least some college or received a degree, and almost half of the sample reported having participated in research in the past. Desire to increase one's own knowledge and advance medicine and improve health disparities were the most commonly reported reasons for participating in the registry.

According to Table 1, several positive associations exist between the demographic characteristics and the direct and indirect recruitment methods, with the exception of radio. Enrollment differed by age for all other methods -existing studies, community outreach, public databases, internet and email. Younger enrollees enrolled via email. Older enrollees enrolled via public databases and existing studies. Having two or more medical conditions was associated with these five recruitment methods, while a history of hypertension was associated with existing studies, public databases, and email. Having participated in research in the past was associated with existing studies, community outreach, public databases, and email recruitment methods. Finally, increasing one's own knowledge or advancing medicine

was the single motivator to participate that was significantly associated with the most number of recruitment methods: internet, email, and radio.

Implementation by recruitment method

At the time of this analysis 608 individuals were enrolled in the Project CONNECT registry. Table 2 details recruitment method by length of recruitment effort, population reach, registry enrollees, staff time to recruit and enroll registry enrollees, and additional costs (e.g., mileage reimbursement for community outreach staff, subcontract with Shaw CSR, and radio advertisement fees). As expected, indirect methods, especially radio and email, reached a greater number of individuals.

Efforts to recruit registry members through existing studies and radio resulted in fewer registry enrollees compared to other methods. Recruitment through community outreach remained the most time-consuming and longest employed method, yet was associated with higher registry recruitment. Outreach settings included urban and rural churches, health fairs and screening events at local community centers, local health focused conferences, African American sorority and fraternity service events, and large African American events such as the Mid Eastern Athletic Conference (MEAC) and Women's Empowerment. Outreach logs tallied 3642 miles traveled (average 58 miles per trip) to 120 events reaching 8303 individuals (range 6-5000; median 166 individuals per event). Outreach events included presentations/conferences (37%), health fairs (34%), outreach sessions (15%), vendor exhibits (13%), and print media (1%).

Individuals recruited through public databases (n=900) were contacted by mail or phone. Two-thirds of contact attempts were not completed due to incorrect phone or mailing address (382 individuals) or soft refusals (217 individuals). We were able to make contact to 301 individuals. Of these, 63 enrolled in the registry via mail or phone and 181 respondents verbally declined. The remaining 57 individuals hung up on the interviewer, or deferred enrollment due to extended illness or desire for additional information and time to review it.

Discussion

In this study we describe a multi-pronged approach to develop a registry to enhance African American participation in research and identified associations by age. Younger participants enrolled in the registry via email and internet methods. Older registry participants enrolled via public databases and existing studies. However, participants across the age spectrum enrolled following direct contact through community outreach. The direct face-to-face contact required for this method is recognized as a successful strategy for recruiting older adults [24, 40, 41] who view the outreach interaction as reciprocal [42]. This method is also demonstrated with limited attrition compared to other methods [43]. Community outreach is an appropriate method for reaching an age diverse African American population, particularly those with limited research experience. However, if the intent is identify a diverse array of African American participants, then a combination of direct and indirect recruitment methods may best reach African Americans with varied demographic characteristics, health status, and research experiences. This is consistent with an examination of recruitment strategies and the investigators who utilize them. Quinn and colleagues [44] distinguished characteristics of comprehensive researchers, who employ multiple strategies including active strategies, from traditional researchers who use fewer strategies overall that can be categorized as passive strategies. They suggest researchers who possess expertise in multiple techniques may be better able to tailor strategies to target populations.

While our findings suggest the use of multiple or a combination of recruitment methods may be needed to reach and enroll a diverse study sample, doing so may be beyond the resources and expertise of individual investigators. For example, investigators using direct outreach methods to identify and recruit minorities report that the accrual benefits come with costs that may be up to five times higher than typical efforts to reach and recruit white participants [45-47]. However, developing an institutional resource, as is the case for the CONNECT Registry, could be an important step for supporting institutional missions to reach and recruit minority participants. Academic centers committed to health disparities research might consider devoting the resources needed to develop an infrastructure such as a minority registry. A thoughtfully designed infrastructure may not only serve the accrual goals of the researcher and institution, but also improve relationships with communities of color and further advance health disparities research.

Evidence of successful minority recruitment and retention strategies can be demonstrated when the goals of minority and research communities are matched [41] and communities have access to research opportunities and summary findings [24, 39]. The development and enforcement of the NIH public access policy signifies a benchmark in addressing this concern [48]. A centralized recruitment registry would establish an accessible setting for community members to seek out studies. Potentially the registry can also disseminate research findings through newsletter, community forums, and awareness of the public access policy.

Limitations

We acknowledge several limitations to our study. First, based on our findings, we cannot say whether registry participants' expressed interest in learning more about research will translate into participation in research. Additional studies of decision-making when presented with research opportunities will be needed to determine how participation in a registry with periodic contact can facilitate research participation. Contemplation of research participation may be an important step towards informed decision-making about research participation.

Second, exposure to multiple recruitment methods was a possibility. Unintended overlap of recruitment methods was unavoidable in this project. However, community-focused strategies that increase familiarity with study purpose and access to study information have been found to be complimentary to recruitment goals [49]. Thus, registry members repetitively exposed to the Project CONNECT name, logo, and staff through multiple community events, radio announcements, newsletters, and promotional items over the time period reported here could have attributed a positive cumulative influence and sense of familiarity of the name and purpose of Project CONNECT.

Finally, as presented in the results, the majority of the sample included minority participants. Though the prevalence of minorities in our sample provides valuable information to respond to our research focus on minority study recruitment, future studies should strive to collect data from more ethnically diverse and larger samples in order to present more generalizable and applicable findings. Similarly, the majority of our sample reported a higher level of education than national data may generally find. This was most likely due to our recruitment sites at health fairs and conferences. Again, in order to avoid similar limitations in sample biases, future studies should consider recruitment and data collection from a diverse collection of settings that are not as academically emphasized.

Conclusions

Diverse representation in clinical and behavioral research that reflects the diversity of the larger population continues to challenge generalizability and relevance of research findings. The methods used in the development of the Project CONNECT registry demonstrate effectiveness in recruiting African Americans with diverse age range and experiences with research. The direct and indirect methods discussed here highlight the importance of awareness and opportunity in the decision-making experience for potential research participants and the relevance of multi-pronged recruitment methods to reach and engage diverse populations.

Acknowledgments

Project CONNECT is supported by grant funds from National Center on Minority Health and Health Disparities (P60 MD000244 and P60 MD000239), and the National Research and Services Award (T32HP14001) from the Health Resources and Services Administration. The authors would like to recognize and express their gratitude to the The Shaw University Comprehensive Research Center of Excellence University, the Shaw University Survey Research Unit, and the Project EXPORT Community Advisory Board for their guidance on the development of recruitment methods and strategies. We are appreciative of Natasha Blakeney, Zoe Enga, Toni Davis, Michelle Hayes and student interns for their dynamic efforts to implement those strategies. We also thank Richard Youngblood and Justin Lucas for editing assistance. Finally we extend our most sincere thanks to the all of the churches, community organizations, and registry members for their interest and participation in the CONNECT registry.

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Table 1

Demographic profile of Project CONNECT registry enrollees (n=608)

	EXISTING STUDIES			DIRECT METHODS n (%)			INDIRECT METHODS n (%)			Total N (%)
	n	p	%	n	p	%	n	p	%	
Total N	14		268	63		75	182		7	608
Age										
18-29	0	****	53 (19.8)	2 (3.2)	****	29 (38.7)	78 (42.9)	****	2 (28.6)	164 (27.0)
30-39	1 (7.1)	*	56 (20.9)	4 (6.4)	**	18 (24.0)	43 (23.6)		2 (28.6)	124 (20.4)
40-49	0		57 (21.3)	7 (11.1)	*	14 (18.7)	27 (14.8)		0	105 (17.3)
50-59	4 (28.6)		56 (20.9)	11 (17.5)		12 (16.0)	24 (13.2)	*	3 (42.9)	110 (18.1)
60-64	2 (14.3)		17 (6.3)	10 (15.9)		2 (2.7)	5 (2.8)	*	0	36 (5.9)
65+	7 (50.0)	****	29 (10.8)	29 (46.0)	****	0	5 (2.8)	****	0	69 (11.4)
Female	2 (14.3)	****	188 (70.2)	33 (52.4)	****	57 (76.0)	137 (75.3)	*	6 (85.7)	423 (69.6)
Married	9 (69.2)	**	104 (38.8)	22 (34.9)		22 (29.3)	61 (33.5)		2 (28.6)	220 (36.2)
Current health status (good/very good/excellent)	11 (84.6)		231 (87.5)	49 (77.8)		67 (91.8)	171 (94.0)		6 (85.7)	535 (88.0)
Reports 2 or more medical conditions	7 (53.9)	****	45 (16.8)	23 (36.5)	****	6 (8.0)	19 (10.4)	**	2 (28.6)	102 (16.8)
African-American (vs. Caucasian)	14 (100.0)		268 (100.0)	63 (100.0)	**	71 (94.7)	178 (97.8)	****	7 (100.0)	600 (98.7)
Have you participated in research in the past? (yes)	10 (71.4)	*	82 (30.6)	18 (28.6)	****	37 (49.3)	128 (70.3)	****	5 (71.4)	279 (45.9)
School education (some college and beyond)	9 (20.0)		212 (79.1)	28 (44.4)		67 (89.3)	168 (92.3)	****	6 (85.7)	490 (80.6)
Health conditions (yes):										
Asthma	0		19 (7.1)	5 (7.9)		4 (5.3)	16 (8.8)		3 (42.9)	47 (7.7)
Cancer	5 (38.5)	****	15 (5.6)	5 (7.9)		0	0	****	1 (14.3)	25 (4.1)
Diabetes	4 (30.8)	**	23 (8.6)	13 (20.6)	****	4 (5.3)	11 (6.0)		2 (28.6)	57 (9.4)
Hypertension	7 (53.9)	*	67 (25.0)	30 (47.6)	****	8 (10.7)	26 (14.3)	**	2 (28.6)	140 (23.0)
Mental health	0		5 (1.9)	0		6 (8.0)	5 (2.8)	**	1 (14.3)	17 (2.8)
Reasons that motivated individuals to participate:										
Minority health/health disparities	1 (7.1)		24 (9.0)	3 (4.8)		0	42 (23.1)	****	0	70 (11.5)

	DIRECT METHODS n (%)				INDIRECT METHODS n (%)				Total N (%)
	Existing Studies	p	Community Outreach	Public Databases	Internet	Email	p	Radio	
Helping the black communities/ self/others	5 (35.7)	****	26 (9.7)	2 (3.2)	0	**	14 (7.7)	0	46 (7.6)
Increase own knowledge and advance medicine	4 (28.6)		48 (17.9)	5 (7.9)	1 (1.3)	****	42 (23.1)	**	101 (16.6)
Monetary incentive	1 (7.1)		2(0.8)	2 (3.2)	3 (4.0)		16 (8.8)	****	25 (4.1)
Info on specific diseases	2 (14.3)	*	16 (6.0)	4 (6.4)	0	**	1 (0.6)	**	23 (3.8)
Career	2 (14.3)	*	10 (3.7)	0	2 (2.7)		13 (7.1)	*	26 (4.3)
Other	0		10 (3.7)	7 (11.1)	0	*	13 (7.1)	0	30 (4.9)

P values calculated using chi square for significance.

* p<.05

** p<.01

*** p<.001

**** p<.0001

Table 2

Project CONNECT registry enrollees and recruitment method (N=608)

Recruitment Method	Time period (Months)	Reach	Enrollment*	Person time	Additional costs	Staff time per enrolled participant (hours)	Yield by method
<i>Direct Methods</i>							
Existing Studies	2	500	14 (2%)	172	-	12.29	.0280
Community Outreach	54	8303	268 (44%)	3401	\$1858	12.69	.0323
Public Databases	4	900	63 (10%)	313	\$5813	4.97	.0700
<i>Indirect Methods</i>							
Radio	1.5	80000	7 (1%)	20	\$10000	2.86	.0001
Email	27	42317	182 (30%)	55	-	.30	.0043
Internet	27	7685	75 (12%)	55	-	.73	.0098

* Percentages rounded and do not add to 100%