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Characterizing Researchers by Strategies Used for Retaining Minority Participants: Results of a National Survey

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Abstract

Limited attention has been given to the optimal strategies for retaining racial and ethnic minorities within studies and during the follow-up period. High attrition limits the interpretation of results and reduces the ability to translate findings into successful interventions. This study examined the retention strategies used by researchers when retaining minorities in research studies. From May to August 2010, we conducted an online survey with researchers (principal investigators, research staff, and IRB members) and examined their use of seven commonly used retention strategies. The number and type of retention strategies used, how these strategies differ by researcher type, and other characteristics (e.g., funding) were explored. We identified three clusters of researchers: *comprehensive* retention strategy researchers - utilized the greatest number of retention strategies; *moderate* retention strategy researchers - utilized an average number of retention strategies; and *limited* retention strategy researchers - utilized the least number of retention strategies. The comprehensive and moderate retention strategy researchers were more likely than the limited retention strategy researchers to conduct health outcomes research, work with a community advisory board, hire minority staff, use steps at a higher rate to overcome retention barriers, develop new partnerships with the minority community, modify study materials for the minority population, and allow staff to work flexible schedules. This study is a novel effort to characterize researchers, without implying a value judgment, according to their use of specific retention strategies. It provides critical information for conducting future research to determine the effectiveness of using a combination of retention strategies.

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Keywords

Retention; Strategies; Racial and Ethnic Minorities; Research

Introduction

To conduct robust studies with generalizable results, researchers must recruit sufficient numbers of representative participants. Barriers to recruitment are well-documented and substantive prescriptive literature exists [1–4] detailing the challenges of recruiting racial and ethnic minorities. Although less has been written about *retaining* minorities within studies and during the follow-up period, there is some literature that suggests retention is more problematic with minority participants and consequently, threatens the generalizability of study results [5–7]. For example, loss to follow-up in longitudinal cohort studies occurs when participants drop out or when investigators lose track of participants [6]. High attrition limits the interpretation of results, reduces statistical power, prolongs studies [5], and impacts the people whom the research ultimately aims to affect. Thus, strategies used to retain minorities in research studies are essential.

Since recruitment has been accepted as the cornerstone of sound research, there is less information on retention [5, 7]. There are a limited number of studies that specifically report retention rates across different racial and ethnic groups and fewer studies that report the impact race and ethnicity has on retention [6–10]. Loss to follow-up is a complex occurrence that has been associated with numerous other factors such as age, gender, disease severity, strength of ethnic identity and psychological distress [11–15]. Nevertheless, certain barriers to retention, lack of transportation, interference with work and family responsibilities, financial cost, and cultural mistrust, may affect minorities differentially [16–19].

While many studies have grappled with the issue of retention of minorities in research, much of the literature on optimal strategies for retention consists of “lessons learned” rather than empirical evidence [17, 20]. A wide variety of retention strategies are reported in studies with predominantly minority participants, including use of financial incentives, flexible scheduling, community-based settings and support, transportation, and ease of scheduling and appointments [7, 8, 12, 18, 21–30]. Several systematic and other reviews report on optimal strategies for retaining minorities in research studies, and generally the results suggest that using multiple methods that combine incentives (monetary compensation, gift cards, and small tokens of appreciation) and flexibility with community-based activities (by providing extended hours for data collection - early morning, evening, weekend; shortened clinic visits; contacting participants via home and telephone visits, and postal mail) generally yields the highest retention rates among minority participants [5, 6, 24, 31–33].

Until now, there has not been a national study that specifically examined the retention of minorities in research studies from the researcher’s perspective. We report the results of a national survey of researchers (principal investigators, co-investigators, and research staff) and IRB members in which we examined minority retention strategies. Our study is the first to examine and characterize these researchers according to the number and types of retention strategies used, and to describe how these strategies differed according to specific researcher characteristics - their background, training, funding, and type of research conducted. This study was approved by the University of Pittsburgh Institutional Review Board and included in our agreement with the University of Maryland.

Methods

Sample

The participants were recruited beginning in May 2010 via an email invitation to complete an online survey from May 2010 to August 2010. Invitations to participate were sent through the list serves of Public Responsibility in Medicine and Research (PRIM&R), which includes researchers and IRB members that conduct a wide variety of research studies, PRIM&R webinars, Community-Campus Partnerships for Health, selected clinical and translational science institutes across the country, which include a diverse set of investigators, and researchers affiliated with academic health centers. We also utilized publications and social media to issue invitations to participate; these included the IRB Advisor and Facebook sites for the Centers for Disease Control and Prevention, the American Public Health Association, and the Journal of Medical Ethics, to name a few [34].

In the invitation to participate, we did not define “conduct of minority research.” Rather, we were particularly interested in researchers’ opinions about recruitment and retention of racial and ethnic minorities in research studies and engaging minority communities in the research process. The invitation informed the participants that they will be asked questions about the racial and ethnic groups with which they typically conduct their research, barriers in recruitment and retention of minorities, attitudes toward community engagement, actions taken to increase recruitment and retention, experiences working with minority communities as well as researcher demographic characteristics. The researchers were not required to have a minimum number of minority participants in their studies during the May to August survey timeframe.

Measures

Retention strategies—Participants were asked if they used the following strategies for retaining participants in research studies: 1) sharing presentations and publications with participants, 2) celebrating research study milestones, 3) providing reports on study progress to participants, 4) making periodic telephone calls to participants, 5) sending birthday cards, 6) mailing newsletters to participants, and 7) focusing deliberately on building a strong relationship between research staff and participants. This list of retention strategies is not exhaustive. Certain strategies (sending birthday cards) can be considered as incentives and as flexible visit options (making periodic telephone calls to participants). Noticeably, all of the abovementioned strategies can be used when attempting to retain any type of research participant, including minority participants, and are commonly seen in the literature for this purpose [5, 6, 17]. Participants could add “other” retention strategies in an open field of the survey. The survey is available upon request of the authors.

Funding—We measured nine sources of funding: 1) National Institutes of Health (NIH), 2) Centers for Disease Control and Prevention (CDC), 3) Agency for Health Care Research and Quality (AHRQ), 4) National Science Foundation (NSF), 5) Veterans Administration (VA), 6) Department of Defense (DOD), 7) philanthropic foundations, 8) pharmaceutical companies, and 9) other. Participants answered yes or no to each funding source, and they could select multiple funding sources.

Barriers to retention of minorities in research—Participants selected specific steps they took to overcome retention barriers: 1) worked with a Community Advisory Board, 2) hired minority staff, 3) developed new partnerships with the minority community, 4) modified study materials for the minority population, 5) flexibility in staff work schedules, and 6) other. This list of steps is not all-inclusive. Decidedly, the list was chosen from the literature [5, 6, 17] and from the authors’ extensive experience conducting community-based

intervention studies that promote healthier lifestyles (e.g., avoiding smoking, increasing physical activity, HIV risk reduction, diabetes self-management, etc.). Moreover, these studies focused on increasing minority participation in research and on determining retention barriers and ways to overcome them.

Types of research—Participants were asked to identify the primary area of research they conducted by checking all that applied: 1) behavioral and epidemiologic studies, 2) clinical trials, 3) evaluation research, 4) health outcomes research, 5) health services research, 6) intervention research, 7) observational studies, and 8) other [34].

Demographics—Seven demographic variables were measured: gender, age, race, ethnicity, place of work or employment, primary role in research, and years involved with research.

Analyses

A k-mean cluster analysis was performed on the seven retention strategies. The number of clusters was chosen based on interpretability of the three identified clusters. The cluster group memberships were validated by performing cross-tabulations with funding and type of research. The chi-square, p-value, and Cramer's V (effect size) are reported. One-way between-subjects analysis of variance (ANOVA) was performed on continuous dependent variables. The analyses were performed using STATA Data Analysis and Statistical Software.

Results

Three hundred forty seven participants had a primary or secondary role as researchers [130 PI/Co-I (37.5%), 149 research staff (42.9%), and 68 IRB members (19.6%)]. We excluded IRB staff that did not also have a role as a researcher. Moreover, two hundred sixty five (76.4%) participants completed the survey and 249 of them completed all seven items regarding the strategies used to retain minorities in research studies. Seventy-nine percent of the participants were female and the mean age of the participants was 46.8 years (SD = 11.8). There was no significant difference between participants who completed the survey and those who did not by researcher type (PI/Co-I, research staff, IRB), race, and gender. Approximately 43% of participants who completed the survey had six or more years of federally funded grants versus only 25.9% of participants who did not complete the survey ($\chi^2(1) = 7.50, p = .006, \text{Cramer's } V = .148$). The participants were involved in conducting research for an average of 14 years (SD = 9.1) [34].

A k-mean cluster analysis was performed on seven strategies in retaining minorities in research studies. The seven items were coded "used" versus "not used." Although we considered multiple cluster solutions, among the 249 participants who completed all seven items, three clusters were discovered. Further analysis of the clusters revealed there were 73 participants (29%) in cluster 1, 100 participants (40%) in cluster 2, and 76 participants (31%) in cluster 3. There were significant differences between the three cluster groups on retention strategies used (Figure 1). The mean number of strategies used in the cluster 1 was 1.4 (SD = 1.28). Members of this group will be referred to as the *limited* retention strategy researchers; they were more likely to use the smallest number of retention strategies. The mean number of strategies used in the cluster 2 was 3.1 (SD = .95). These are the *moderate* retention strategy researchers who were more likely to use an average number of retention strategies. The mean number of strategies used in the cluster 3 was 5.4 (SD = 1.08). We refer to these as the *comprehensive* retention strategy researchers. Comprehensive retention strategy researchers were more likely to use the highest number of retention strategies.

We examined the differences between the three clusters by comparing their use of the retention strategies (Figure 1). Six strategies were used by the majority of comprehensive retention strategy researchers except sending birthday cards (36%). Most of these researchers focused deliberately on building a strong relationship between their research staff and participants (96%), provided reports on study progress to participants (98%), and shared presentations and publications with participants (97%). The moderate retention strategy researchers mainly used two strategies: making periodic telephone calls to participants (100%) and focusing deliberately on building a strong relationship between research staff and participants (88%). Approximately half of the limited retention strategy researchers used focusing deliberately on building a strong relationship between research staff and participants (52%) and sharing presentations and publications with participants (41%).

There was no significant difference among the three retention strategy cluster groups by demographic variables (Table 1). Thirty-four percent of the comprehensive and 17% of the moderate retention strategy researchers received CDC funding compared to only 8% of the limited retention strategy researchers ($\chi^2(2) = 17.88, p < .001, \text{Cramer's } V = .268$). There was no other significant difference concerning other types of funding received by the three retention strategy researcher groups (Table 2).

However, there were significant differences on two types of research conducted by the three retention strategy researcher groups: health outcomes research and other (Table 3). Fourteen percent of the comprehensive and 21% of the moderate retention strategy researchers performed health outcomes research compared to only 7% of the limited strategy cluster group. Twenty-six percent of the limited strategy cluster group performed other research compared to only 14% of comprehensive and 12% of the moderate retention strategy cluster groups. There were significant differences in the steps taken to overcome barriers to retention of racial and ethnic minority participants among the three cluster groups (Table 4). Comprehensive and moderate retention strategy researchers were more likely to use all six steps to overcome retention barriers at a higher rate than the limited retention strategy researchers. The majority of comprehensive and moderate researchers worked with a community advisory board, hired minority staff, developed new partnerships with the minority community, modified study materials for the minority population, and allowed staff to work flexible schedules.

Although we cannot report responses to the online survey questions by cluster, we did receive verbatim responses on retention strategies used and actions taken to overcome barriers. As for additional strategies used to retain racial and ethnic minority participants, respondents reported: returning telephone calls from participants the same day; sending weekly postcards on study events; targeted communication about the study in tribal newspapers, radio, Facebook pages and email; careful tracking of appointments, including working with other providers; maintaining a website with study publications; and sending a study synopsis to participants.

Discussion

Failure to retain racial and ethnic minorities in research studies is an ongoing and vexing issue for researchers [17, 24, 28], and an important methodological concern [31]. Given the expense of conducting research and the limited financial resources to accomplish it, the effort to reduce loss to follow-up with its resulting introduction of bias is an important research priority [31]. High attrition threatens the internal and external validity of studies [31], limits the ability to draw inferences [31], prolongs studies [6], and ultimately reduces the ability to effectively translate the results into successful interventions. This

notwithstanding, although the literature on strategies to retain participants in research studies offers some promising practices [17, 20, 31], there is sparse evidence concerning the specific strategies used by researchers that maximize the retention of minority participants [31]. Consequently, our study is unique in that it is the first national study to characterize investigators according to the number and types of retention strategies used and to describe how these strategies differed based on specific investigator characteristics.

We identified three clusters of researchers: *comprehensive* retention strategy researchers who utilized the greatest number of retention strategies; *moderate* retention strategy researchers who utilized an average number of retention strategies; and *limited* retention strategy researchers who utilized the least number of retention strategies. These descriptors do not imply a value judgment of one group versus the other. We were interested in describing differences between the three groups based on retention strategies used. For example, both the comprehensive and moderate retention strategy researchers were more likely than the limited retention strategy researchers to use a range of retention strategies (e.g., hiring minority staff, allowing the staff to work flexible hours, modifying study materials for the minority population, working with a community advisory board, etc.). The use of a range of retention strategies is consistent with previous literature, which suggests that studies with the highest retention of minorities include retention plans with multiple varied strategies that combine incentives and flexibility with community-based activities [5, 6, 24, 31–33].

Hunt and White's review [6] indicate the strategies needed to maximize participant retention include forming community advisory boards, staff training, providing incentives, participant bonding or identification with the study, and increased contact frequency. We recognize that the comprehensive and moderate retention strategy researchers took other steps (e.g., mailing study newsletters, building strong relationships, telephone calls, community advisory boards) that may have fostered participant bonding or identification with the study and increased contact frequency with the participants. Furthermore, Davis and colleagues [33] noted that studies with the highest retention rates used a combination of strategies. Contrariwise, Robinson and colleagues' review [31] of retention strategies point out those studies with lower retention rates (i.e., less than the mean rate of 86%) reported the use of fewer strategies than those studies with higher retention rates. Future research could examine the extent to which the number of strategies used, and cluster type, impacts retention rates.

Another distinguishing characteristic that defines the three cluster groups is the types of research conducted. Comprehensive and moderate strategy researchers were significantly more likely than the limited strategy researchers to conduct health outcomes research that examines the end results of health services by taking patients' experiences, preferences, and values into account [34]. This finding leads to a logical next research step. Specifically, can this finding – investigators who use more steps to overcome retention barriers and conduct health outcomes research – be replicated in another study.

This study has several limitations. We acknowledge that a large portion of our sample was comprised of female investigators and we could not calculate a response rate. Furthermore, we did not collect quantitative data on each researcher's retention successes or their use of flexible data collection methods. We recognize that our sample recruitment could have been accomplished via other methods. Although another method would have been to identify and survey investigators publishing research articles with minority samples, the scope and cost of that approach was beyond this specific study. Conversely, our choices of groups like Public Responsibility in Medicine and Research (PRIM&R), which included a broad group of researchers that conduct a wide variety of research studies that include minority

participants and researchers from selected US clinical and translational science institutes gave us access to a diversity of research areas. Nevertheless, based on this approach to recruitment of participants, there may be selection bias that affects external validity. Internal validity may well have been compromised if the e-mails soliciting survey completion went to more of one type of researcher than another; however, we do not believe that was the case.

The k-mean cluster analysis is limited with respect to finding different types of clusters (i.e., non-spherical shapes or widely different size or density). This limitation is minimized by representing three clusters and verifying the results with separate cluster algorithms. Since the cluster analysis is a data driven technique, the reproducibility of results is limited. If our sample size was large enough, we could have performed a cross-validation and this limitation would have been avoided. Yet, by examining the distributions of variables and the heterogeneity in the data, the likelihood of finding the relatively low and high clusters is good. There were clear differences between the cluster groups on the amount and types of retention strategies used.

Nevertheless, the study presented here has notable strengths. It enhances our understanding of the retention process and provides critical information for additional research that explicitly evaluates the effectiveness of using a combination of retention strategies. It may be particularly appropriate to focus on testing those retention strategies with higher costs, in terms of research expense (hiring and training minority staff, overtime pay for research staff working flexible hours on weekends and holidays) [31]. Furthermore, the testing of retention strategies that are long term, can be built over time, and are relatively low in cost (developing and maintaining new partnerships with the minority community and working with a community advisory board) are warranted. Future research could expand beyond our study to include a comparison of the costs and benefits of utilizing different retention strategies.

Continuing, research is needed that determines whether the effectiveness of different retention strategies is dependent upon research type conducted (i.e., clinical versus behavioral). Some promising research by Quinn et al [35] found two distinct clusters of researchers who utilized a differential number and types of recruitment strategies with minority participants. Given that Quinn and colleagues found two clusters, and this study yielded three clusters, we examined the data and found only a moderate association between retention and recruitment clusters (Cramer's $V = .31$). This lends support to the finding that researchers may indeed use different recruitment than retention strategies. It would be interesting to explore the extent to which there is any synergy between those who utilized more community-based strategies for recruitment follow similar strategies for retention.

Although the preponderance of US researchers tends to be male, our research revealed an overwhelmingly female respondent group. Future research might explore whether gender directly affects the willingness of researchers (non-minority or minority) to use a complex paradigm of retention strategies. An assessment of the experiences of minority researchers is called for to understand if they are more successful in their retention efforts. Likewise, we may assume that minority researchers have an "easier time" recruiting *and* retaining minority participants. Yet, to our knowledge, this subject has not been empirically tested. Overall, it is essential to understand researchers' characteristics, knowledge, skills, and experiences, including their impact on retention rates.

We view the recruitment *and* retention of racial and ethnic minorities as two critical components of the research process, with retention being a distinct phase that begins during recruitment when strong relationships can be established. As a result, we suggest that

researchers consider developing retention plans that include various retention strategies including, but not limited to e-mail and postal mail; site and home visits; the use of individualized, technology-based strategies - telephone calls to multiple contacts to locate participants who have moved [36] and strategies from the study reported here. Maintaining a good tracking system that includes scheduling and calendar software to monitor follow-up of participant contacts throughout the study period is an invaluable component of retention plans [5]. These plans would consist of listing each retention strategy with description, delineating the action items for carrying out the strategy, and identifying those who are responsible for these activities and the related deadline(s). The underlying premise is that retention plans are important aspects of research designs and can further allow for recognizing any factors that facilitate and hinder retention among specific populations.

Conclusion

This national study is the first to specifically examine the retention of racial and ethnic minorities from the researcher's perspective. We examined and characterized the researchers (principal investigators, co-investigators, and research staff) and IRB members according to the number and types of retention strategies they employed and described how these strategies differed according to specific researcher characteristics - their background, training, funding, and type of research conducted. Three clusters of researchers, each one uniquely different, emerged from the analysis based on the number of retention strategies they utilized to retain minorities in public health, and biomedical research, including clinical trials.

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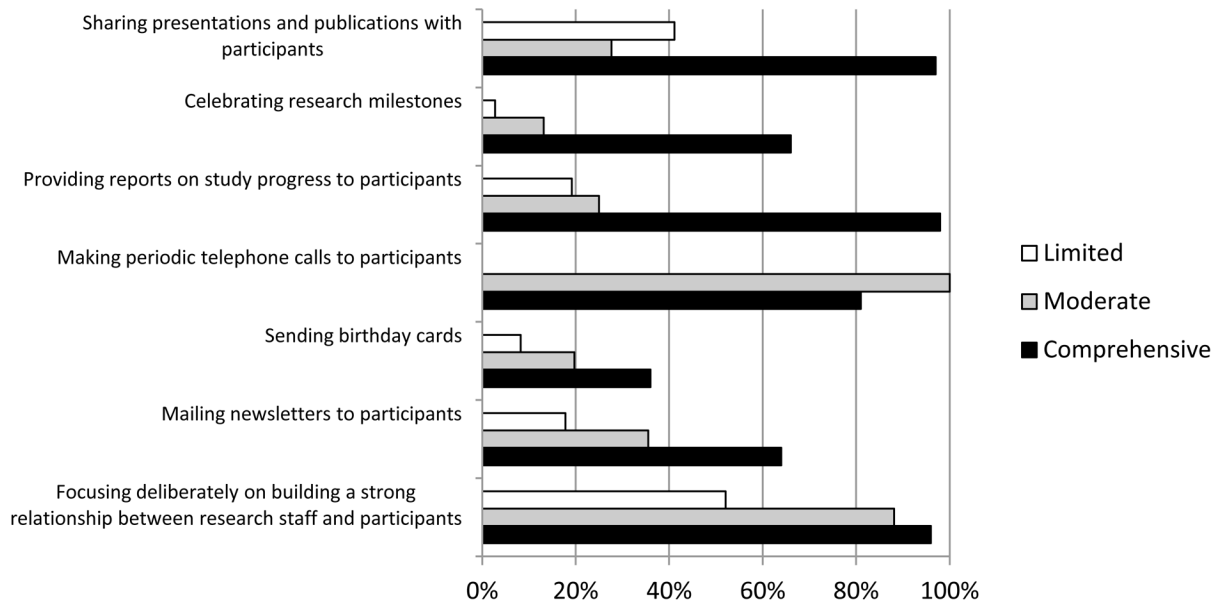


Figure 1.
Retention Strategies Used by the Three Cluster Groups of Researchers

Table 1

Demographic Variables by Cluster Group Membership

	Retention Strategy Cluster Groups			2	P	Cramer's V
	Limited	Moderate	Comprehensive			
Race				5.73	0.454	0.108
White NH	59%	62%	56%			
Black NH	12%	20%	19%			
Hispanics	16%	11%	9%			
Others	12%	8%	15%			
Sex				1.56	0.458	0.079
Male	23%	17%	16%			
Female	77%	83%	84%			
Work				2.87	0.581	0.079
University	72%	61%	62%			
Hospital	10%	17%	14%			
Other	18%	23%	24%			
Research Role				1.41	0.843	0.053
PI/Co-I	42%	36%	41%			
Staff	40%	49%	44%			
IRB	18%	16%	15%			
Age				F	P	2
Mean (SD)	47.0 (11.67)	44.03 (12.06)	47.6 (10.59)	2.29	0.103	0.019

Table 2

Funding Sources for the Three Retention Strategy Cluster Groups. Numbers in the “Cluster Groups” columns indicate the percentage of researchers in each group who indicated they receive or have received funding from each source.

Type of Funding	Cluster Groups			χ^2	p	Cramer's V
	Limited	Moderate	Comprehensive			
NIH	58%	67%	68%	2.03	0.362	0.090
CDC	8%	17%	34%	17.88	<0.001	0.268
AHRQ	3%	1%	7%	4.06	0.132	0.128
NSF	8%	1%	3%	5.05	0.080	0.142
VA	10%	9%	7%	0.45	0.798	0.043
DOD	1%	5%	8%	3.75	0.153	0.123
Foundation	30%	37%	39%	1.50	0.472	0.078
Pharmaceutical Companies	14%	22%	19%	1.89	0.389	0.087
Other	36%	33%	30%	0.61	0.736	0.050

Type of Research Conducted by Each Cluster Group. Numbers in the “Cluster Groups” columns indicate the percent of researchers in each group who are involved with the different types of research.

Table 3

Type of Research	N	Cluster Groups			χ^2	p	Cramer's V
		Limited	Moderate	Comprehensive			
Behavioral & Epidemiologic Studies	104	33%	46%	45%	3.38	0.185	0.116
Clinical Trials	75	19%	36%	34%	5.92	0.052	0.154
Evaluation Research	43	16%	13%	21%	1.91	0.385	0.088
Health Outcomes Research	35	7%	21%	14%	6.22	0.045	0.158
Health Services Research	36	15%	16%	13%	0.30	0.859	0.035
Intervention Research	51	11%	24%	25%	5.80	0.055	0.153
Observational Studies	29	8%	16%	11%	2.14	0.343	0.093
Other	42	26%	12%	14%	6.32	0.042	0.159

Table 4

Steps Taken to Overcome Barriers to Retention of Racial and Ethnic Minorities by Each Cluster Group. Numbers in the “Cluster Groups” columns indicate the percent of researchers in each group who used this strategy to overcome retention barriers.

Strategy Used to Overcome Retention Barrier	Cluster Groups			χ^2	p	Cramer's V
	Limited	Moderate	Comprehensive			
Worked with a community advisory board	38%	47%	63%	10.83	0.004	0.209
Hired minority staff	36%	53%	66%	15.65	<0.001	0.251
Developed new partnerships with the minority community	44%	49%	68%	11.73	0.003	0.217
Modified study materials for the minority population	41%	51%	71%	16.40	<0.001	0.257
Flexibility in staff work schedules	27%	58%	69%	30.23	<0.001	0.348
Other	8%	8%	8%	0.01	0.997	0.005