



## 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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### 1. 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.

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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 have 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.

## 2. Methods

### 2.1. Sample

The participants were recruited beginning in May 2010 via an e-mail 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.

### 2.2. Measures

#### 2.2.1. 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.

#### 2.2.2. 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.

#### 2.2.3. 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

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