

# Relationships and Communication in Minority Participation in Research: Multidimensional and Multidirectional

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We examined the range and nature of investigators' communication and relationship building as they recruit minority participants in their research. Semistructured, in-depth interviews were conducted with 33 investigators conducting research with human participants. The response rate was 77%. Investigators described several kinds of relationships that are formed or called upon when including minority participants in research. The relationships ranged from study-related, short-term interactions geared solely to facilitate recruitment to others that were longer term, extending beyond a particular project. The data suggest that a range of relationships is important as investigators seek to include minority populations in research. These relationships can both facilitate the recruitment process as well as aid in the interpretation of research findings.

**Key words:** communication ■ minorities ■ recruitment

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## INTRODUCTION

Relationships and communication have been noted to be foundational in research that engages minority communities in research.<sup>1-7</sup> An emphasis on relationships underscores the fact that recruitment

for research occurs in the context of social and historical factors that shape how individuals and communities view research participation.<sup>8-10</sup> The types of relationships that may exist among participants, community members and researchers are varied and can be critical to the success of community-based projects and interventions.<sup>10,11</sup>

Increasingly, members of and leaders in minority communities expect to develop genuine partnerships with researchers and, thus, research conducted in a participatory model has become an attractive alternative.<sup>12,13</sup> Participatory research involves open, consistent and deliberate communication among all stakeholders and has been shown to be more acceptable to minority participants than study designs with little community involvement and input in the research process.<sup>1,5,14-19</sup> In those studies where relationships are built through active and ongoing communication, relevant, sustainable interventions and improved health of the communities that participate are more likely to result.<sup>3,6,18-21</sup>

While acknowledged as a fundamental strategy, there has been little empirical research that describes or analyzes the range of relationships and communication patterns that may develop as researchers seek to engage minority participants in research. As noted, the literature has focused on relationships between participants and investigators, often emphasizing the process of research in a participatory research model where power and hierarchy within that relationship are explicitly addressed.<sup>4,6,22,23</sup> However, what is missing from the current literature is a broader description of the patterns of other types of research relationships that are formed during research that seeks to engage communities of color—those created between investigators during research or those between investigators and research participants outside of a participatory research model—and the possible impact of these relationships on the research process. The purpose of this article is to explore these various relationships and to present perceptions of the impact of these relationships on the conduct of research.

## METHODS

### Participant Identification and Recruitment

We sampled investigators from three southeastern universities [one a historically black university (HBCU)] conducting research involving adult human participants in the year 2000. We identified investigators by using institutional review board lists of active studies. We also searched university websites and the Computer Retrieval of Information on Scientific Projects (CRISP) database of NIH-funded biomedical research projects maintained by the NIH Office of Extramural Research. Using the title of the study and any available description of the studies (e.g., abstracts), the investigator list was stratified by institution, whether the investigator had a history of NIH funding, and whether their current work focused on minority health or health disparities. We chose these strata since we felt these characteristics may be important in the recruitment experience and wanted to ensure the fullest range of responses. The investigator sample was generated using random selection within these strata for the two non-HBCUs and included all eligible investigators from the HBCU. We excluded investigators who were not conducting research involving human participants (e.g., secondary analysis of an existing data set or biologic specimens). See Table 1 for an overview of participant selection and recruitment.

Investigators were first contacted by a letter that included a brief description of the project and an invitation to participate in the study. Using a prepared recruitment script, principal investigators (PIs) were then contacted by telephone to further explain the nature of the study and verify eligibility. We made up to four attempts to contact investigators using both telephone and e-mail.

### Data Collection

The PI (GCS), a health disparities researcher, conducted in-depth, semistructured interviews with investigators lasting from 30–50 minutes. The interview guide and all protocols were approved by the University of North Carolina’s institutional review board. Using a structured guide, the interviewer asked open-ended

questions, followed up participants’ responses, pursued themes as they arose, and sought clarification or elaboration as required. Interviews were conducted between November 2001 and January 2003. The interview guide covered the following topics: recent experience with recruitment; strategies used to recruit minority participants; use of race as a variable in research/analyses; and assessment of the NIH mandate to increase minority participation in clinical research. We used the term “minority” to refer to all racial/ethnic minorities but did not define it explicitly for the respondents, nor did we refer to a specific ethnic or minority group. Using structured probes, opportunities were consistently made available for participants to express their opinions. Interviews were audiotaped and transcribed for analysis. At least two members of the research team listened to each interview transcript to verify the accuracy of the transcription and to remove all identifiers.

### Analysis

We analyzed interview transcripts using the principles of grounded theory. Glaser’s method of constant comparative analysis requires the data to be reviewed in light of an initial conceptual framework and coded multiple times.<sup>24</sup> This method allows the investigator to discover underlying uniformities in the original set of categories. The codes were developed inductively using an iterative process. At regular research meetings, we reviewed all new transcripts for emerging themes, extant codes were revisited, and we repeatedly refined the coding scheme. Written definitions for each code were developed and revised based on input from all research team members. The code book also included examples and directions for when and when not to use the code. Sample size was not set prior to the data collection. Instead, we enrolled participants until no new concepts arose during analysis of successive interviews, i.e., theoretical saturation.

Each transcript was coded separately by two of three research team members (GCS, CB, JD). While reviewing the transcribed interviews, we analyzed all statements that related to interpersonal communication. We sorted the statements into categories, modifying the codes

**Table 1. Participant selection and recruitment**

	Total	Yes	No (Refused)	Ineligible	Unable to Be Reached	Percent Completed
Interview						
Non-HBCU						
Federal funding and minority focus	12	9	1	1	1	75%
Federal funding and no minority focus	12	8	3	1	0	67%
No federal funding, minority focus	7	7	0	0	0	100%
No federal funding, no minority focus	7	3	1	1	2	43%
HBCU	9	6	2	1	0	67%
Total	47	33	7	4	3	70%

and themes as needed. Results were discussed in coding team meetings, and any differences between coding pairs were reconciled. In addition, two senior members of the research team (GH, SE) coded randomly selected transcripts and were included in the coding meetings to reconcile the codes. In this form of analytical triangulation, important insights can emerge from the different ways people look at the same set of data<sup>25</sup> and can also provide a means to ensure internal validity. For the analysis of the research questions addressed in this manuscript, two investigators (GCS, ICW) reviewed all coded transcripts and, after several iterations, agreed on four domains reflecting the types of relationships formed. The domains, analysis and interpretation of the results were again reviewed and refined in larger team meetings. We used ATLAS.ti 4.2 software for organization, management and analysis of the qualitative data.

**RESULTS**

We contacted 43 eligible investigators and conducted 33 interviews (response rate=77%). Characteristics of the investigator-participants in this study are presented in Table 2. Twenty-two of the 33 respondents conducted research with a focus on minority health or communities. The majority were full/associate professors (57%), women (64%) and white (67%) investigators.

In evaluating investigators' discussions of minority recruitment and the inclusion of minority participants in research, two predominant types of communication patterns emerged: one-to-one or interpersonal communication, and one-to-many or community level communication. Within these two modes of communication, we found relationships that ranged from study-related, short-term interactions geared solely to facilitate recruitment to those that were longer term, extending beyond a particular project. Below we describe the themes that arose within each of these four areas (two communication modes and two types of relationships within each communication mode). Table 3 contains additional quotes for each dimension and theme described below.

**One-to-One/Interpersonal Communication**

**Short-term study-related relationships.**

*Recruitment facilitators.* Most investigators described some type of short-term relationship that was formed expressly to facilitate recruitment of minority participants. Some described the importance of communication in the investigator-participant relationship during direct recruitment for a study, often in the clinical setting. The importance of trust, rapport-building and tailoring communication to the needs, education or literacy level or understanding of the potential research participant were emphasized. One investigator noted:

*If they're college educated or graduate school educated, then you need to make sure that whatever that educational level is, that you approach that level because you can talk to someone all day about a genomic project, but they may not understand what genomic means.*

Other investigators described the importance of establishing rapport with individual community members who might serve as liaisons between the principal investigator and potential research participants. For example, one investigator said:

*... I would suggest that they do what I did. Find—go through informal, social network of a community. Make contact with leaders, whether they be church members or social service networks or senior activity center, wherever elderly people congregate. You go to where the people congregate. You work through the leaders and you, in essence, make it seem safe. You get, if you will, an introduction into, to the target group of patients that you're interested in interviewing.*

Development of rapport was seen as important in establishing the credibility and sincerity of the investigator as well as raising awareness of the study in the target community.

**Table 2. Demographic and professional characteristics of principal investigators (N=33)**

Investigator Characteristic	N	%
PI Race		
White	22	67
Black	11	33
PI Sex		
Male	12	36
Female	21	64
Academic Rank*		
Assistant professor	7	21
Associate professor	8	24
Full professor	11	33
Other	6	18
Professional Degree		
MD	12	36
Other doctoral degree	19	58
Other	2	6
Minority Focused Research		
Yes	22	67
No	11	33
HBCU†		
Yes	6	18
No	27	82

\* Data missing for one principal investigator; † Historically black college or university

*Technical advisors.* Investigators also described seeking advice from colleagues, community members or senior mentors specifically on the technical aspects of recruitment strategies to be used in a particular project. For example, one person noted:

*... there should be colleagues in most places that could and would be willing to facilitate that process ... for your research design, in the more technical aspects of it, I would suggest to identify mentors for recruitment positions, or for the whole recruitment process."*

**Long-term relationships extending beyond a project.**

*Mentoring relationships.* Several investigators emphasized the importance of longer-term one-to-one relationships that extended beyond the period of a particular study. These relationships often took the form of mentoring of investigators by professional colleagues or community members. For some investigators, these relationships and interactions served two purposes. First, they ensured that the investigator was on the right track for a particular recruitment strategy. Secondly, these mentors served as a sounding board for difficult issues related to race and social class. Investigators involved in such longer-term relationships described the mentors as a member of a minority group who was trusted as a scientist, or as someone who understood the science and was honest and supportive in

**Table 3. Themes on communication by investigators recruiting minorities into research**

Domain	Theme	Subtheme
One-to-One/Interpersonal Communication Short-Term Study Related	Recruitment facilitators	
	Technical advisors	
Long-Term Extending Beyond a Project	Mentoring relationships	Technical aspect of recruitment
		Sounding board
		Acting as mentor

talking about the “hard stuff” about race and racism in the context of research. One researcher advised others to:

*involve some minority investigators to sort of make sure that you know you are culturally sensitive ... I think that they provide a reality check. I don't think I would understand all the issues necessarily.*

These mentoring relationships were also described as sometimes bidirectional. A few investigators who felt they had successful relationships in minority communities also described serving as a mentor or role model, using their established relationships to help junior investigators in their recruitment efforts.

## One-to-Many/Community-Level Communication

### Short-term study-related relationships.

*Community advisors.* Investigators described short-term, study-related relationships with community leaders or community advisory boards that were convened for a particular study. These relationships were formed primarily to get advice about recruitment strategies that would be acceptable to the target populations and raise awareness of the project within a particular community. Investigators also sought out high-profile persons to endorse the study.

*Investigator visibility.* Several investigators described the importance of being visible as the principal investigator to community members, who are potential and actual research participants. Being physically present dur-

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### Example

"We used key persons in the community to provide us with an entrée to the minority populations we were targeting..."

"I hired one of the administrative assistants to be my recruiter ... to just kind of talk up the study to anybody who came in the door. And I gave her a bunch of flyers ... the initial plan was that she would post flyers throughout the agency and, people would come in and inquire about the study and talk to the administrative assistant and say 'you know, what's up with this study?' And she would talk it up and make people real excited."

"She's been giving some advice and direction ... about interviewing somebody, did we want to have somebody of the same race, ... and trying to be sensitive [to] some of the issues, she's helped me build some bridges with some collaborators at some of the sites. The persons are not minority, but they work in this minority setting and have experience, so they helped build some relationships at the sites."

"I think it's key at the site where you're going to recruiting that you have a good relationship ... if you have a site where's a predominantly minority population, if you can develop a relationship with them, maybe collaborate with them. I think it goes a long way in facilitating your recruitment... I had actually a relatively easy time; the initial letter I sent out to the people, of potential participants, was signed by myself and the people from the daycare agency."

"I worked with a mentor very carefully, the previous summer before I did this study. I talked a lot with her as well as other interviewers ... they're experts on this. ...I had a lot of different people I could talk to about what's the going rate for doing an interview, what are some of the things I need to consider? What are some impediments, to my recruitment process?"

"...it's really important to get a person of that minority group, whom they trust, to work with them if they were not from that group and that culture ... and by "trust" I mean two things. One thing I mean is trust their competence as a scientist or trust their competence as a community leader ... but you need somebody else on your advisory group or on your team that is [from that cultural group] ... But the other thing is to develop a trusting enough relationship so that you can talk about the hard stuff to talk about that has to do with, in my case, racial issues."

"I worked on a study that looked at an extremely racially charged topic ... in that research it was absolutely critical to have minority representation on the scientific team [to help ]interpret those results appropriately and fairly."

"...one of the stages I've reached now in my research is that I can facilitate for other people, [and] build on the relationships that we've been building over time."

ing recruitment efforts and during day-to-day operations of the study was seen as essential to establishing trust and as a way to convey the sincerity of the investigator and the research team. As one investigator put it:

*[Being visible in the community was done] mainly to give me credibility, or who I was, ... that I was doing a study, and it had been approved and all of that kind of information, but I think that gave them a level of trust to respond to me when I then called to see if they were willing to participate and set up an appointment.*

*Building trust.* Trust was the central theme in all of the community-level interactions. Although investigators commented on having some successes in recruiting minority participants, other investigators described their university or academic affiliations as a barrier to trust, challenging their recruitment process. This distrust arose from perceptions of exploitation by university researchers of community members, both in recent experience and historically. For example, one investigator noted:

**Table 3. continued**

Domain	Theme	Subtheme
One-to-Many/Community-Level Communication Short-Term Study Related	Community advisors	
	Investigator visibility	
	Building trust	
Long-Term Extending Beyond a Project	Sharing insights	
	Forming networks	
	Investigator obligations	

*I don't think if you go out into the community to say "hey, I'm from [a university], I'm doing this research study," people are going [to] just come running; because we don't have a good history of treating people well ... There's a lot of distrust of the academic community and particularly here in [this city]. I don't think [the university] has a really good reputation for having positive interactions with the community. And I think that there's a lot of potential ... to come off almost as pimping the community.*

Another investigator had a similar opinion:

*Sometimes family members are very suspicious of physicians and their motives. And sometimes it's because they've heard about the Tuskegee study and we have to spend time talking about that. And they're worried [about] being a guinea pig, and what they're really worried about: is it going to hurt them?*

### Example

"They're various members of the community [that] have come on board to help us recruit members of the community ... So, knowing faces such as a senator or, someone who's an editor of the local magazine or a radio personality, who all happen to be parts of our board. They recognize them quicker than they would mine. Therefore, they've been very instrumental in recruiting."

"... in order to make an impact on community members ... they have to see the investigator's face. ...And once that familiarity is there, then it makes the public more accessible or more susceptible to join in, you know, not feel like they've been coerced."

"That has to be coupled I think with a good effort prior to the launching of the research of what we call 'community awareness and preparation' so that as the process is evolving the community is aware of it to the extent that the funding, or the extent that the resources allow that to happen."

"[When we presented the study data] sometimes people took it as inflammatory in terms of just one more negative thing to say. So, it elicits a dialogue. So, [I would recommend] the full presentation of [what the results are] and really begin to listen. The other thing is to engage in a process that really is collaborative to the extent that it can be collaborative, in the sense that individuals really do know that you're listening to what they say and they understand and you represent that you really don't have all the answers because if you had all the answers you wouldn't be there."

"You really establish connections that go beyond your actual study population. You get to know all kinds of people in the communities in which you're working. And that has the advantage of providing you with a lot more contacts."

"And so how you get around that is by having positive, strong relationships with the community. And so, in my situation, I knew the executive director for this community based organization. I had been working on the advisory board for the CBO for a little, at least some time, up to a year or so. She knew I wasn't gonna just do the research and get out, but that I was really interested in women's health and women's outcomes...so really you have to have close relationships with someone in the community and you have to be genuine I would say, and not just come off as 'I'm here to get my subjects,' I don't even like that word! ... You can't have that kind of attitude."

"How would I give the results back to them? I mean ... I think it's important to try to do this so that people hear, 'a researcher came in and talked to us. This is what they found.' ... so, at least they'd have the opportunity. Because people do appear to resent that."

"so one of the things we have done over the years is invested a lot of time in developing the kinds of relationships that facilitate recruitment. And in the long run, it has paid off ... . And then the other part is that once you had established these kinds of relationships, they don't go away if you treat them with respect. So, in the long run, it actually for all parties involved works out a lot better."

"...you wind up being more than the researcher. They tell you things. They want to ask you things ... You get to listen to them ... trust is the biggest thing [even in] the small things."

**Long-term relationships extending beyond a project.**

*Sharing insights.* One dimension of longer-term community-level relationships was how investigators drew on the strengths and insights of individuals who lived in and were integral members of a community. An investigator described making the transition in their outreach efforts from using community recruiters to “community consultants.” These consultants were groups of individuals who the research team consulted with regularly before, during, and after a project on changing dynamics of the community.

*Forming networks.* In addition, investing time and energy in these longer-term relationships was seen as necessary to forming networks that could facilitate future recruitment efforts. For example, one investigator stated that:

*I think a lot of [my recruitment success] had to do with the long-term relationships I've established with a large number of these patients ... I don't see this as experimenting on people so much as participating in a process that ultimately is going to makes us better.*

*Investigator obligations.* Another dimension of these long-term relationships included the obligations of investigators once these relationships had been formed. These obligations were for investigators to either report results back to community leaders and study participants, or to act as a resource person within the university that community members could call upon for other service-related activities (e.g., church presentation) that were not tied directly to recruitment. For example, one investigator mentioned talks that were given on topics outside of the research context:

*We're going to a deacon's meeting and we're just talking about rheumatoid arthritis and lupus. So, you get known in the community, and that can be very helpful.*

As investigators described these relationships, they recognized and respected the value of these relationships and the trust that results. As described by one investigator:

*And they (participants/community members) really feel like we care about them. I mean, that is what they say over and over again. "I never felt cared about by any healthcare providers before. You don't just do it for the paycheck. You really care about us." And we do. I mean, they're telling the truth.*

**When relationships are not formed.** Two investigators described unique instances where they questioned the relevance and importance of forming these relationships. One investigator described the conflict of seeking out and investing time in a mentoring relationship related to minority recruitment and the competing concerns of academics, such as writing papers and grant proposals. Another described a missed opportunity to connect with an African-American minister active in the community:

*At the time, he was on sabbatical and wasn't able to meet with me and a variety of things, and I wondered if that would have been a good strategy. I didn't use that strategy, but it was going to take an enormous amount of time to start that process. And, of course, in the crunch of writing grants and trying to make a decision, I didn't do that.*

Another investigator felt that in population-based studies community involvement was not always feasible or practical:

*... a lot of people were saying "you know, you're going about this wrong and you should find local leaders and churches and stuff like that." But the problem is, for a population-based study, we have everybody in the whole state. It doesn't work.*

**DISCUSSION**

We found that the clinical investigators in this study formed and called upon a variety of relationships in their efforts to include minority participants in research. Most investigators described short-term relationships with the explicit purpose of facilitating recruitment. These instrumental relationships were formed with individuals and groups, such as community liaisons, research facilitators and community advisory boards. However, many other investigators described developing longer-term relationships that extended beyond a particular project. In addition to serving as a catalyst for future recruitment efforts, these long-term relationships, at both the individual and group level, seemed to play an important role in how investigators consider issues around race/ethnicity in their work and the obligations that they may feel they have to communities they engage in research projects.

The importance of developing instrumental relationships, especially as it pertains to minority participation in research, has been described by several authors.<sup>8,26,27</sup> These relationships are noted as critical in establishing investigator credibility and as a necessary prelude to demonstrating the trustworthiness of the research team.<sup>28,29</sup> Building on the established networks of individuals or groups of individuals (e.g., community advisory boards) has been described as one important strat-



egy to understanding community dynamics and thus possibly improving success in minority recruitment.<sup>30,31</sup>

However, there has been a growing emphasis on relationships that begin before and extend after a particular study or project.<sup>7,32-34</sup> The call for extended relationships has typically been borne out of the need for cultural sensitivity in research designs and sustainability of interventions.<sup>5,35-37</sup> To that end, participatory research methods are based on the premise of partnerships that draw on the unique strengths of community and academic partners, and call for reciprocity and equity regarding the benefits of the research.<sup>22,23,38</sup> In this paradigm, all aspects of the research process, from developing research questions to interpretation and dissemination of findings, are determined jointly and collaboratively by the involved partners. Research that uses a participatory approach is thought to lead to more thoughtful and relevant research questions that result in more sustainable interventions.<sup>3,6</sup>

In view of the inarguable appeal of the principles and processes just described, the question arises whether, given the rewards of long-term relationships, are short-term instrumental relationships ever a preferred or even sufficient research strategy? There are circumstances where limited relationships may be appropriate, such as cross-sectional studies where the study team has no hypotheses about difference by race/ethnicity, or studies that are not focusing on problems relevant to a particular racial or ethnic minority community. However, in light of previous research abuses, as exemplified by the U.S. Public Health Study at Tuskegee, and the resulting deep-seated mistrust in minority and other underserved communities in the clinical research enterprise, we believe instances where only instrumental relationships are formed should be limited. We would suggest that when an investigator seeks to understand and address differences by race/ethnicity in health or healthcare that longer-term relationships become more important, if not essential. As investigators in this study describe, these relationships can be invaluable not only when investigators seek guidance on culturally appropriate research designs but also in contributing to more informed and thoughtful interpretation of findings.<sup>11,26</sup> In our view, when engaging individuals from minority communities, to understand racial and ethnic differences by race, investigators should seek cultural and historical information from members of those communities to make sense, rigorously and responsibly, of research findings. As others have suggested<sup>6</sup> and the investigators in this study observed, these relationships bring with them obligations that should lead researchers to question their own positions of privilege when approaching underserved communities. This requires rethinking priorities and paying as much attention to *how* research is conducted as to *what* research is conducted.<sup>8</sup>

Our findings should be interpreted in light of the limitations of this project. We approached this research question using qualitative methods which, inherent to

this methodology, limit the generalizability of these findings to those we interviewed. We should also acknowledge the potential bias introduced by the interviewer, an African-American woman conducting health disparities research, and that the characteristics of the interviewer may have introduced social desirability to some of the responses. As a research team, we carefully weighed the benefits of request for and conduct of an interview conducted by a colleague (rather than interviewing "up" by research staff) against the bias that might be introduced by the race and research focus of the interviewer. In an attempt to mitigate this possible bias, all questions were carefully worded to place distance between the topic and the interviewer, and all interviews were conducted by telephone unless an in-person interview was explicitly requested by the investigator-respondent (n=2). Another possible limitation in our work was that we asked investigators about their recruitment experiences regarding minorities as a group, rather than asking them to explicitly discuss different minority groups and how strategies for different groups might differ. We fully recognize that culturally appropriate strategies to recruit one minority group may not be applicable to another group.<sup>39</sup>

As research on health and healthcare increasingly focuses on the differential risks and diversity among populations, the nature of research relationships has become more important. We found that investigators form relationships that are instrumental in recruitment of minority participants but also may aid in the interpretation of their research findings. However, more empirical work is needed to demonstrate how these short- and longer-term relationships influence the type of research that is done and ultimately what effect they have on the health of minority communities. Do longer-term relationships that are collaborative beyond the time of the study lead to greater cultural awareness of the investigator, and do they in turn contribute to increasing rigor and sophistication of their investigations of health disparities? In clinical relationships, communication that is participatory has been demonstrated to lead to higher patient satisfaction with the encounter.<sup>40,41</sup> Given the variety of research relationships that we found are formed in the process of recruiting minority participants, it would be important to examine how these types of communications impact recruitment success and possibly study-related outcomes within studies.

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## After May 23, 2007, healthcare providers must have a National Practitioner Identification Number.

To find out more about obtaining an NPI Number please contact 1-800-464-3203 or go online: <https://nppes.cms.hhs.gov/NPPES/StaticForward.do?forward=static>. instructions.

Please review the NPI Final Rule pdf on the above-mentioned web page for more details.