

Research Expectations Among African American Church Leaders in the PRAISE! Project: A Randomized Trial Guided by Community-Based Participatory Research

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Including African Americans in research has become an important challenge faced by investigators hoping to address disparities in health. Investigators engaged in research involving underserved populations are acutely aware of the role of historical events and current experiences with medical care in contributing to distrust of medical research.^{1–4} A recent report suggests that African Americans are significantly more likely than their White counterparts to believe that medical research exposes them to unnecessary risks and that they do not receive a full explanation of the implications of research participation.⁵

Investigators sensitive to these issues often look to the African American church as a way to reach members of this community,^{6–12} and they see community-based participatory research (CBPR) as an approach that can help address some of these barriers.^{13–23} Use of participatory approaches can help overcome distrust by fostering open and honest communication about the research process and engagement of participants in study planning and implementation. The CBPR approach views community participants as partners in the research process rather than as subjects on whom research is conducted.^{13,15}

As investigators approach churches to become research partners, engagement of pastors and other church leaders is critical to program acceptance and success. Pastors in the African American church can play a pivotal role in the adoption of health promotion and research activities.^{6,8,24} The pastor's introduction and endorsement of a program to his or her congregation is essential to any such effort. Because pastors face considerable demands on their time and extensive responsibilities both inside and outside the church, they often rely on the assistance of lay church leaders.

Although the role of pastors and other church leaders is fundamental to health disparities research efforts, little is known about their expectations regarding community-academic partner-

Objectives. This study sought to examine the expectations and satisfaction of pastors and lay leaders regarding a research partnership in a randomized trial guided by community-based participatory research (CBPR) methods.

Methods. Telephone and self-administered print surveys were administered to 78 pastors and lay leaders. In-depth interviews were conducted with 4 pastors after study completion.

Results. The combined survey response rate was 65%. Research expectations included honest and frequent communication, sensitivity to the church environment, interaction as partners, and results provided to the churches. Satisfaction with the research partnership was high, but so was concern about the need for all research teams to establish trust with church partners.

Conclusions. Pastors and lay leaders have high expectations regarding university obligations in research partnerships. An intervention study based on CBPR methods was able to meet most of these expectations. (*Am J Public Health.* 2003;93:1720–1727)

ships or the degree to which they believe these expectations are met at the conclusion of a research endeavor. Without an understanding of these expectations, researchers are likely to fail in their attempts to engage church leaders and their members in research collaborations. Initiating a research partnership without a full understanding of expectations may result in decisions and actions that further violate the trust of the African American church community. Not only can distrust adversely affect the immediate research relationship and, in turn, the validity of the data collected, it can have a profound effect on the future willingness of minority populations to engage in the research enterprise.

In this article, we present data regarding the expectations of pastors and other church leaders participating in a research partnership, Partnership to Reach African Americans to Increase Smart Eating (PRAISE!), as well as the degree to which they felt that their expectations were met. This study partnership implemented many principles of CBPR.

METHODS

Overview of PRAISE!

PRAISE!, funded by the National Cancer Institute, was a 5-year randomized study

(1996–2001) that included 60 churches in 8 North Carolina counties.¹² The project was designed to identify barriers to and motivators of dietary change among African Americans; to develop a theory-based, culturally sensitive intervention; and to test this 12-month intervention in a randomized trial. The major dietary outcomes were intake of fat, fruits, vegetables, and fiber. Also collected were biochemical measures related to dietary intake and psychosocial data to assess determinants of behavioral change. PRAISE! was designed as a multilevel intervention with particular attention to cultural appropriateness, long-term sustainability within the church environment, and potential for dissemination to other interested churches. A description of the design and implementation of the intervention has been published elsewhere.¹²

We implemented many elements of CBPR in the PRAISE! research partnership, with church and community members engaged early in the process and throughout the project. In the purest form of CBPR, community members determine the focus of the research question; however, because this project was funded in response to a program announcement from the National Cancer Institute, we were confined to an emphasis on cancer pre-

vention. Nonetheless, throughout the project the study team relied on input from members of the church community to guide the nature and structure of the intervention. Church leaders and community members hired as staff were involved with decisions about survey design and implementation and about approaches to collecting anthropometric and biochemical data.

Study Design

After baseline data collection, recruited churches were randomly assigned by county to intervention and control conditions. Measures were collected at baseline and again following the 12-month intervention, with extensive process data collection throughout the study period to assess program implementation, acceptability, and feasibility. Feedback from pastors, reinforced by that from early recruits to the study, suggested that participation in a nutrition intervention program was considered highly desirable. Concern was expressed that control-group churches would feel left out. In consideration of this concern, PRAISE! investigators designed the study with a delayed-intervention control group, providing intervention training and materials to control-group churches after follow-up data collection.

Recruitment of PRAISE! Churches, Pastors, Church Leaders, and Church Members

The recruitment process consisted of enumerating all African American churches within a county and mailing letters of invitation to the pastors. The pastors of churches expressing an interest in participating were asked to sign a memorandum of agreement, to appoint a church liaison to handle the research interface with the church, and to appoint a health action team (HAT) leader. The HAT leader or the pastor then recruited 4–7 members to serve on the HAT team and take primary responsibility for implementing the intervention. The PRAISE! Intervention was designed to reach all members of the church who attended with some regularity. We recruited a “measurement group” consisting of 15–35 volunteers from each church to complete pre- and postintervention blood draws and surveys.

Intervention Implementation

Pastors played a very significant role in introducing PRAISE! to the church, recruiting lay leaders to guide the intervention, and supporting the effort throughout. They were offered 3 health promotion workshops during the course of the intervention to provide training and materials and to facilitate an exchange of ideas for spiritually related strategies to encourage healthy eating among their congregations. The HAT leader and team were responsible for implementing the intervention within the church. Interventions (described in detail in elsewhere)¹² were designed to provide adequate structure for those unfamiliar with nutrition program implementation and enough flexibility to permit adaptation to the specific needs and circumstances of each church as a means to promote sustainability.

Survey Development

Survey questions were developed according to the results of a focus group among African American pastors and extensive guidance from a pastor, serving as a paid consultant, who had prior experience with research projects. Items were designed to be closed ended, but an option for additional open-ended responses was included with nearly every question.

Survey administration. After the 12-month intervention period, pastors (intervention and delayed intervention), church liaisons, and HAT leaders were asked to respond to follow-up surveys. Pastor surveys were conducted by phone interview, and church liaisons and HAT leaders completed self-administered print surveys. The pastor surveys were conducted by individuals not directly associated with the PRAISE! implementation team to encourage honest responses about any concerns with the project. Although the surveys for each respondent group varied in their content, a number of questions regarding participation in a research partnership with a university were identical, or nearly identical, in all 4 surveys. This report analyzes the survey data related to basic sociodemographic characteristics of the church leaders, their reasons for participating in PRAISE!, their assessments of their congregations' willingness and readiness to participate in research, their expectations of a church–university partnership, their beliefs about the degree to which these expectations were met, and their appraisals of the value of

the PRAISE! research endeavor to themselves and their congregations. Frequency distributions were generated to describe the attributes of the church leader groups. Because of the similarity in response distributions of the church liaisons and HAT leaders, those 2 groups of respondents were categorized as “Lay Leaders.”

In-depth interviews with pastors. As part of another project concerning the potential for existing research projects to help link investigators with community-based study partners, we conducted in-depth interviews with 4 PRAISE! pastors in 2 different groupings after completion of the PRAISE! project. They were asked to discuss their concerns about research, suggest how researchers could improve their approach, and consider how they would feel about new researchers asking to contact them on the basis of a prior established research partnership.

RESULTS

Survey Data

Survey respondents. Respondents included 24 of 30 church liaisons (response rate=80%), 20 of 30 Health Action Team leaders (response rate=67%), 23 of 30 intervention group pastors (response rate=77%), and 11 of 30 delayed-intervention group pastors (response rate=37%). Lay leaders (church liaisons and HAT leaders) were predominantly employed females aged 35 to 65 years, the majority (79%) of whom had attended college (Table 1). The lay leaders were more often long-term church members who were highly involved in church activities. Table 1 shows that the pastors were also well educated, with 79% having a college degree or higher. Nearly half (47%) of pastors were aged 35 to 50 years, 35% were aged 51 to 65 years, and 15% were aged 65 or more years. More than a quarter (29%) of the pastors held jobs outside the clergy, most (74%) had led their church for at least 5 years, and 91% had been a member of the clergy for at least 5 years.

Reasons for participation. All church leaders were asked to select their top reasons for agreeing to participate in PRAISE! Interest in cancer prevention (n=15), nutrition education (n=15), and concern for their congregations' health were most commonly cited among the pastors' top reasons for PRAISE! participation (Table 2). For the lay leaders, the wish to increase their

TABLE 1—Sociodemographic Characteristics of Church Leaders

Characteristic	n (%)
Lay leaders (n = 44)	
Age, y	
< 35	7 (16)
35–50	16 (37)
51–65	15 (35)
> 65	5 (12)
Gender	
Male	3 (8)
Female	36 (92)
Education	
< High school diploma	1 (2)
High school diploma or GED	8 (19)
Some college	15 (35)
College degree or higher	19 (44)
Employment	
Employed outside the home	31 (74)
Retired	7 (17)
Other	4 (10)
Length of membership, y	
1–4	7 (16)
5–10	7 (16)
11–20	5 (12)
> 20	24 (56)
Level of involvement in church activities	
Rarely/occasionally	1 (2)
Usually	13 (30)
Always	29 (67)
Pastors (n = 34)^a	
Age, y	
< 35	1 (3)
35–50	16 (47)
51–65	12 (35)
> 65	5 (15)
Education	
< High school diploma	1 (3)
High school diploma or GED	1 (3)
Some college	5 (15)
College degree or higher	27 (79)
Current nonclergy employment	
Yes	10 (29)
No	24 (71)
Tenure as pastor of the church, y	
1–4	9 (26)
5–10	13 (38)
11–20	8 (24)
> 20	4 (12)
Years in the clergy	
1–4	3 (9)
5–10	4 (12)
11–20	18 (55)
> 20	8 (24)

Note. GED = general equivalency diploma.
^aAll pastors were male.

TABLE 2—Leaders' Reasons for Participation in PRAISE! and Leaders' Assessments of Congregations' Willingness and Readiness for PRAISE! Participation

	Intervention Group, No. (%)	Delayed-Intervention Group, No. (%)
Pastors		
Top 2 reasons for participating in PRAISE!		
Interest in cancer prevention	11	4
Interest in nutrition education	11	4
Concern about health of congregation	5	7
Getting church more involved in health	6	4
Personal nutritional concerns	9	0
Interest of congregation	2	3
Other	1	4
Congregation's willingness to participate in PRAISE! when first informed of the opportunity		
Extremely willing	11 (48)	6 (55)
Somewhat willing	10 (43)	4 (36)
Not very/not at all willing	2 (9)	1 (9)
Congregation's willingness to participate once activities started ^a		
Extremely willing	16 (70)	—
Somewhat willing	7 (30)	—
Not very/not at all willing	0 (0)	—
Congregation's readiness to undertake research component of PRAISE! when first informed ^a		
Extremely willing	5 (22)	—
Somewhat willing	14 (61)	—
Not very/not at all willing	4 (17)	—
Congregation's readiness to form research partnership with a university ^a		
Extremely willing	9 (39)	—
Somewhat willing	12 (52)	—
Not very/not at all willing	2 (9)	—
Lay leaders		
Top reason for participating in PRAISE!		
Getting church more involved in health	12 (28)	—
Interest in health	10 (23)	—
Wanted to help congregation members	10 (23)	—
Personal/family cancer concerns	5 (12)	—
Personal nutritional concerns	3 (7)	—
Interest in nutrition	2 (5)	—
Pleased to be asked to take on the role	1 (2)	—
Congregation's willingness to participate when first started to plan events		
Extremely willing	16 (36)	—
Somewhat willing	24 (55)	—
Not very/not at all willing	4 (9)	—

^aOnly intervention group pastors were asked this question.

church's involvement in health-related issues (n=12), their own interest in health (n=10), and their desire to help their congregations (n=10) were the most common reasons for wanting to participate (bottom of Table 2). Table 2 shows that church leaders reported that

their congregations were willing to participate in the intervention. Pastors were somewhat less certain of their congregations' willingness to form a research partnership with the university, although this certainty improved after the initiation of the project.

TABLE 3—Leaders' Perceptions of the Characteristics of a Good Church–University Research Partnership

	No. (%)		
	Intervention Group Pastors	Delayed-Intervention Pastors	Lay Leaders
Involvement of church boards and/or other church leaders in planning and decisionmaking			
Not/somewhat important	4 (17)	2 (18)	4 (9)
Very important	9 (39)	6 (55)	26 (59)
Extremely important	10 (43)	3 (27)	14 (32)
Honest and complete description of the purpose and requirements of the research project			
Not/somewhat important	2 (9)	2 (18)	0 (0)
Very important	9 (39)	6 (55)	22 (50)
Extremely important	12 (52)	3 (27)	22 (50)
Involvement of study participants or representatives in planning and decisionmaking			
Not/somewhat important	4 (17)	2 (18)	6 (14)
Very important	12 (52)	6 (55)	25 (57)
Extremely important	7 (30)	3 (27)	13 (30)
Frequent communication with the university			
Not/somewhat important	1 (4)	3 (27)	6 (14)
Very important	13 (57)	5 (45)	23 (52)
Extremely important	9 (39)	3 (27)	15 (34)
Adequate help from the university in implementing the project			
Not/somewhat important	2 (9)	1 (9)	0 (0)
Very important	10 (43)	5 (45)	28 (64)
Extremely important	11 (48)	5 (45)	16 (36)
Paperwork kept to a minimum			
Not/somewhat important	6 (26)	1 (9)	3 (7)
Very important	4 (17)	5 (45)	25 (57)
Extremely important	13 (57)	5 (45)	16 (36)
University staff sensitivity to the church environment			
Not/somewhat important	2 (9)	0 (0)	1 (2)
Very important	9 (39)	7 (64)	28 (65)
Extremely important	12 (52)	4 (36)	14 (33)
University commitment to answering questions and hearing concerns			
Not/somewhat important	2 (9)	1 (9)	2 (5)
Very important	10 (43)	5 (45)	23 (52)
Extremely important	11 (48)	5 (45)	19 (43)
Results provided to church when study is completed			
Not/somewhat important	0 (0)	2 (18)	2 (5)
Very important	10 (43)	5 (45)	20 (45)
Extremely important	13 (57)	4 (36)	22 (50)
University providing financial resources to cover costs associated with research project			
Not/somewhat important	4 (17)	1 (9)	2 (5)
Very important	10 (44)	3 (27)	24 (55)
Extremely important	9 (39)	7 (64)	18 (41)

Continued

Expectations Regarding Research Partnerships

Church leaders were provided with a list of 12 possible characteristics of a church–university research partnership and asked to rate each characteristic’s importance. Leaders endorsed the level of importance of each characteristic as not important, very important, or extremely important (Table 3). Although the lack of variability in responses and the small sample sizes preclude statistical comparisons, the lay leaders, who were primarily responsible for implementing the intervention, appeared somewhat more concerned than the pastors about keeping paperwork to a minimum and receiving adequate funding from the university for research tasks. Pastors and lay leaders alike attached strong importance to honest and complete description of study purpose and requirements, adequate university help in implementing the project, university sensitivity to the church environment, university commitment to answering questions and hearing concerns, and dissemination of results to the church on completion of the study.

Perceived Compliance of the University With Research Expectations

After rating the importance of these partnership components, pastors in both groups were asked, “Which three of these do you consider to be the most important parts of the university/church partnership?” followed by “To what extent do you feel [University of North Carolina at Chapel Hill] has met your expectations in this regard?” Response options included disappointing, needs improvement, doing pretty well, and doing very well. For each of the 3 components selected as most important, 77% to 80% of pastors indicated that the University of North Carolina at Chapel Hill (UNC) was doing pretty or very well, and 2 pastors indicated 1 area each in which they were disappointed. The lay leaders were asked a more global question, “To what extent do you feel UNC fulfilled your expectations in its partnership with your church?” Ninety-eight percent of the lay leaders indicated that the university was doing pretty or very well, and 1 person indicated the need for improvement.

Open-ended responses. At several points in the survey, pastors were offered the opportunity to describe additional concerns or recommendations in an open-ended format. All of the responses to 2 such questions—(1) “Would you

TABLE 3—Continued

Research project gives something back to the community			
Not/somewhat important	3 (13)	1 (9)	7 (16)
Very important	11 (48)	3 (27)	21 (49)
Extremely important	9 (39)	7 (64)	15 (35)
University interacting with church participants as partners not research subjects			
Not/somewhat important	2 (9)	1 (9)	6 (14)
Very important	8 (35)	4 (36)	16 (38)
Extremely important	13 (57)	6 (55)	20 (48)

recommend any changes concerning the way project staff at [the University of North Carolina at Chapel Hill] made contact with you about the PRAISE! project?” and (2) “Is there anything I have not mentioned that you think would be important to consider when churches and universities form a partnership?”—are included in Table 4.

Perceived value of research participation. As a method of measuring their beliefs about the value of participating in this research effort, leaders were asked to assess whether PRAISE! participation had been worth their time and their congregations’ time. Both pastors and lay leaders agreed that the research project was worth their own time and that of their congregations (Table 4).

In-Depth Interviews

Responses to the in-depth interviews are presented in Table 5 in terms of the question asked, a summary of responses, and illustrative quotes. Pastors expressed considerable concern about researchers treating them and church members with respect and taking the time to develop a trusting relationship with church partners. They emphasized making sure that the research benefits the community and strongly advocated for using the term research “participant” versus “subject.” Pastors felt firmly that research colleagues of their current research partners should not assume that they have automatic access but should be required to establish the necessary trust needed to begin a research partnership.

DISCUSSION

We found the church leaders had multiple expectations from their university research

partners. Leaders endorsed comments about the importance of communication, cultural sensitivity, support during the project, and giving back to the community in a research partnership. In this trial, which used a CBPR approach, church leaders reported that most of their expectations were successfully met.

Important limitations of this study include the small sample size and the lack of variability in the responses. Had we a larger sample size or more variability, we might have been able to compare intervention with control-group pastors or pastors with lay church leaders or to assess some of the determinants of research expectations and the degree to which the church leaders felt that their expectations were met. These limitations are potentially offset by the utility of quantitative descriptive data on the expectations of church leaders as they enter a research partnership. We believe that our findings will be valuable to those planning or conducting research in African American churches, as well as to those considering CBPR as an approach to health disparities research.

In addition, the possibility of social desirability or bias resulting from nonresponse must be raised, given the overwhelmingly positive responses to participation in PRAISE! in contrast to the high levels of skepticism about research documented by our research team and others.^{2,5} Possible explanations are that our research partners wanted to spare us from any criticism they might have or that all of the critics failed to respond to the survey. We think that both of these explanations are unlikely. The open-ended comments (Table 4) demonstrate our partners’ candor in expressing their concerns and expectations about research. We believe that social desirability might have been a likelier explanation for the positive answers if

these survey questions had been asked at the beginning of the study, before our collaboration had developed.

In terms of possible bias resulting from non-response, none of the 60 churches originally enrolled in the study dropped out, and all 30 of the intervention churches completed all of the 9 interventions that were required as part of the memorandum of agreement. In an attempt to adequately document intervention implementation, church leaders involved with the study were asked to provide extensive documentation.²⁵ This heavy administrative burden, combined with the very demanding schedules of pastors and the multiple volunteer church responsibilities of the lay leaders, made it difficult to reach them for survey completion. Because much of the follow-up survey content related to experience with the intervention, we did not push as hard to obtain responses from delayed-intervention control-group pastors, whose churches had not yet received the intervention training or materials. Thus, we tried to strike a balance between research demands and human needs—energetically striving to collect adequate data while refraining from excessively burdening our church colleagues. We believe that our somewhat limited response rate is more likely attributable to response burden than to dissatisfaction with the partnership.

In considering the role CBPR methods may have played in fostering this positive research partnership, it is helpful to use the framework of the 8 key principles of CBPR, as outlined by Israel and colleagues.¹³

1. Recognize community as a unit of identity. Our data show that pastors and lay leaders were anxious to address health issues within their churches and that they emphasized the need for researchers to be sensitive to the church environment and to take time to develop the necessary trust. Many PRAISE! participants commented that the project helped further church unity by encouraging members to work together toward a difficult but shared goal of improved nutrition.¹²
2. Build on strengths and resources within the community. From the open-ended comments, it is clear that at least 1 pastor felt strongly about the major contributions church members can make to projects such as PRAISE! The issue of

TABLE 4—Leaders' Assessments of PRAISE! Research

	Intervention Group Pastors	Delayed-Intervention Pastors	Lay Leaders
Responses to closed-ended questions			
Participation in PRAISE! research was worth my time and effort			
Strongly agree	14 (61)	5 (50)	17 (41)
Agree	9 (39)	5 (50)	23 (56)
Strongly disagree/disagree	0 (0)	0 (0)	1 (2)
Participation in PRAISE! research was worth congregation's time and effort			
Strongly agree	14 (64)	5 (45)	17 (40)
Agree	8 (36)	6 (55)	24 (57)
Strongly disagree/disagree	0 (0)	0 (0)	1 (2)
Responses to open-ended questions			
Recommended changes regarding the way project staff made contact with you about the PRAISE! Project	Broaden times for blood draws. More clarity in presenting information about the project. Seemed at times to be a breakdown in communication. It appeared that some members "on both sides" felt superior to others. Could have been more assistance given to the liaison because it is a fairly large community.	No comments offered.	—
Anything else that would be important to consider when churches and universities form a partnership?	Interaction with other churches and bringing pastors together. It should be done year after year to be complete for all members to compare results. Information needs to get back to the church so it can be disseminated to benefit others. A [university] representative should spend more time at the eating events. In terms of research, the churches need to receive more consideration in terms of their contributions. In many cases, the churches can do what the academic community can do. Lay people have been doing this for a time. The academic community is looking to the people who they are trying to assist for help. They come up with the idea, but the church can act on that idea. Need community and collaboration to get past the victimization by these groups being separate. Consider the diversity of African Americans in the church group. Understand that the group is diverse and the need to enable leaders to deal with each person as an individual. African Americans are not a homogeneous group. More communication between university and church. Make sure audience is clear on what you are talking about. Make sure you get a commitment. Be honest about the project when you are trying to recruit participants—do not just say something to keep the project going.	Need to follow through on various aspects of the project. The project was a benefit to the congregation, members, and community. Make sure enough finances are available to cover the project. Communication is extremely important. Communication should be enhanced—keeping church updated on results of the study. Adequate materials to give to the church. They did not get enough material.	—

respect for church members as research “participants” and contributors to the research process rather than “subjects” was also an important theme.

3. Facilitate collaborative partnerships in all phases of the research. Church leaders emphasized the need for honest and frequent communication and for interaction in the form of a partnership rather than a top-down approach. They expressed appreciation for the way in which PRAISE! team members conveyed their commitment to establishing a collaborative partnership, stating that church members contemplating a research partnership want to “know how much you care and not how much you know.”

4. Integrate knowledge and action for mutual benefit of all partners. The top 2 reasons given by pastors for participating in PRAISE! were interest in cancer prevention and interest in nutrition education. Most PRAISE! church leaders endorsed the importance of a research project “giving back to the community” and felt that the project had done this. In this regard, intervention research projects have a distinct advantage over observational studies, in which the benefits are not immediately apparent to participants.

5. Promote a colearning and empowering process that attends to social inequalities. Baseline blood draws for PRAISE! were conducted during the time of the Tuskegee apology by President Clinton. This event resulted in numerous pointed questions from church members directed at our research associates and many honest and open dialogues about related issues and concerns. The study team spent many hours discussing how best to address these concerns of church leaders. This time investment may be partly responsible for the positive survey response in terms of UNC’s providing “honest and complete description of the purpose and requirement of the research project.”

6. Employ a cyclical and iterative process. This principle of CBPR speaks to the need for researchers to “roll with the punches” and sometimes adapt the research approach to the needs of study participants while maintaining research integrity. In PRAISE!, it was necessary to enhance the interim intervention for the delayed-intervention control group when it became clear that these churches were contemplating their own nutrition intervention after randomization. By providing training and materials for

TABLE 5—In-Depth Interviews With Pastors After Project Completion

Question	General Response	Direct Quotations From Pastors
What comes to mind when you think about the term “researcher”?	<p>What do they want from me?</p> <p>Concern about how the information will be used.</p> <p>What is the benefit to the participant or the community?</p> <p>Will they view me in a derogatory manner based on how I respond?</p>	<p>I think a lot of persons are so private in that area . . . they have been somewhat concerned about opening themselves up when they hear the word research. It’s, “what is it that I have to share that I really don’t want to share,” and the other concern is how honest and open would they be able to be and not be looked upon in a derogatory sense.</p> <p>I think that some people feel like researchers come in and suck things out of the community and go back and don’t leave anything behind that is positive, so you are thinking both about damage in terms of lack of feeling and lost trust or feeling like they have been mistreated in some way but also feeling that the researchers got a lot more out of it than they did.</p>
What comes to mind when you think of the terms research “subject” vs “participant”?	<p>“Subject” sounds negative.</p> <p>“Participant” means I’m in partnership with the researcher.</p>	<p>When participating in something in my mind it means that I’m actively engaging in a behavior in some kind of way with regard to this project. Subject means to me that I’m being observed, I’m being watched for behavior change or whatever.</p> <p>If I’m a subject it has more of a tone of the little mice that you have in labs . . . the lab rats.</p> <p>To participate I know before hand what is to be expected and what the outcome is going to be. But to be a subject, that involves a lot of ignorance because a lot of people really don’t know what the outcome will be, they are not always up front with the individuals.</p>
What concerns do you have about participating in health-related research?	<p>Research requiring consumption of an unknown product.</p> <p>Researchers being conscious of/respecting my time.</p> <p>Researchers establishing a relationship.</p> <p>Researchers having a respectful attitude toward the participant.</p> <p>Researchers being too clinical and not personable.</p>	<p>The only area that I might be challenged is that if you were giving me something and I had to trust you that whatever you said is as it is. Being honest. I would be challenged . . . however, if my participation only focused or centered on trying to change my behavior regarding something, then those are conscious choices that I was making and going out buying my own food . . . if you weren’t bringing it to me packaged up and telling me it was a particular thing, then I wouldn’t have a problem with it.</p> <p>I think that persons who are researching have got to change their attitudes as well as their actions. If you are wanting to know and really wanting to get into the mind of that individual . . . there’s no other way to do it. You don’t go to the water and drop a hook in front of a fish and expect it to bite. There’s got to be a bait, and I think the bait for the most part is just a decent, respectful kind of attitude toward persons who are participating because those persons don’t have to.</p>
How can researchers best address your concerns?	<p>Meetings like this one.</p> <p>Change attitudes toward participants.</p> <p>Researchers take the time to build trusting relationships.</p> <p>Consider how to keep the spirit of the intervention after the funding is over.</p>	<p>(Regarding an African American researcher from PRAISE!) Yes, she came to our ministry. She actually came at a time where she was at Sunday School, going to workshop and the whole nine yards, . . . people fell in love with her because people felt that she was a part of this and in that short time some kind of relationship was built there . . . if you want to do your research then the relationship has to go above the rest. The relationship has to come first, you can’t come in with the task . . . like “I’m here to do this and you all line up over here.” It’s an old cliché . . . people what to “know how much you care and not how much you know.”</p> <p>You treated us with respect . . . you’d be surprised that some people don’t. Its like you come to some one’s house and you disrespect the man of the house and then you want to work with the wife and kids...you did a very good sell with the preachers first, so once we were onto it, it worked.</p> <p>I tell you, follow-up is very important to any kind of project. There’s your preparation, your actual project, and then there’s the follow-up. That has been the toughest because the funds do dry up . . . it can be discouraging not to be able to continue in that way . . . even if it just means you would have someone to just come back . . . to speak to the church and encourage them.</p>
How do you feel about researchers with whom you have worked sharing contact information with other researchers who may want you to participate in another project?	<p>Not comfortable.</p> <p>Other researchers should take the same steps as PRAISE! researchers—start at ground zero.</p> <p>Would be concerned about sharing of data.</p>	<p>I would say to them that this is not a mailing list . . . same process . . . you go back to ground zero with me. . . I come back to the operative word . . . relationship. I have a relationship with you and not anybody else at [the university], not with the diabetes people or anybody else. It’s all about this for me and if everybody else wants to come to the table, they know the process.</p> <p>I’ve enjoyed the PRAISE! project, but I don’t want my church to turn into a study group for everybody that comes along with a good cause. People need to recognize that no matter how valid they feel that I need information regarding any issue health or otherwise, it’s still a choice that we have to make as to whether or not that is valid for us. Now, they can go through the process of making us agree that it is valid, but it can’t be an assumption or an intrusion upon us as a group.</p>

programs on stress reduction and by looking for opportunities to treat senior adults well, we were able to avoid study contamination while still satisfying the desires of church members to implement health-promoting interventions.

7. Address health from both positive and ecological perspectives. Although the program was funded by the National Cancer Institute and focused primarily on dietary fat, fiber, and fruits and vegetables, it became apparent that church members desired a more holistic perspective on health. Given this request and the similarity of dietary recommendations for prevention of many chronic diseases, we focused on “smart eating” in general, rather than on cancer. Using a more general chronic disease focus allowed us to reflect the concerns of our partners while functioning within the framework of the funding agency.

8. Disseminate findings and knowledge gained from all partners. Our data suggest that receiving study results is a high priority for church partners. This sharing of knowledge is challenging because many of the analyses occur after the funded partnership ends. We have asked for input on publications from church partners and we have shared papers and public relations documents with the churches. It has been important to screen university public relations documents and to negotiate with the writers to ensure cultural sensitivity, particularly in the area of spirituality and health.

In sum, we found that church leaders have high expectations of their university research partners regarding many aspects of the research process and that a randomized trial using CBPR methods can be successful in meeting many of these expectations. We hope that more studies that use CBPR to form partnerships between research institutions and minority communities will help build the trust so critical to fostering high-quality health disparities research. ■

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Contributors

A. Ammerman, C. Washington, and B. Weathers were involved with the PRAISE! Project throughout. They conceived the study, intervention design, and assessment of the intervention. G. Corbie-Smith provided expertise in trust and research expectations and with D.M.M. St. George provided assistance with statistical analysis and interpretation.

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Human Participant Protection

The study was approved by the University of North Carolina's institutional review board.

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