ORIGINAL REPORTS

THE INFLUENCE OF COMMUNITY-BASED PARTICIPATORY RESEARCH PRINCIPLES ON THE LIKELIHOOD OF PARTICIPATION IN HEALTH RESEARCH IN AMERICAN INDIAN COMMUNITIES

Tim D. Noe, MDiv; Spero M. Manson, PhD; Calvin Croy, PhD; Helen McGough, MA, CIP; Jeffrey A. Henderson, MD, MPH; Dedra S. Buchwald, MD

Objectives: Advocates of community-based participatory research (CBPR) have emphasized the need for such efforts to be collaborative, and close partnerships with the communities of interest are strongly recommended in developing study designs. However, to date, no systematic, empiric inquiry has been made into whether CBPR principles might influence an individual's decision to participate in research.

Design, Setting, and Participants: Using vignettes that described various types of research, we surveyed 1066 American Indian students from three tribal colleges/universities to ascertain the extent to which respondent age, gender, education, cultural affiliation, tribal status, and prior experience with research may interact with the implementation of critical CBPR principles to increase or decrease the likelihood of participating in health research.

Results: Many factors significantly increased odds of participation and included the study's being conducted by a tribal college/university or national organization, involving the community in study development, an American Indian's leading the study, addressing serious health problems of concern to the community, bringing money into the community, providing new treatments or services, compensation, anonymity, and using the information to answer new questions. Decreased odds of participation were related to possible discrimination against one's family, tribe, or racial group; lack of confidentiality; and possible physical harm.

Conclusions: Employing CBPR principles such as community involvement in all phases of the research, considering the potential benefits of the research, building on strengths and resources within the community and considering how results will be used is essential to conceptualizing, designing, and implementing successful health research in partnership with American Indians. (*Ethn Dis*. 2006;17[suppl 1]:S1-6–S1-14)

Key Words: Community based participatory research, American Indians and Alaska Natives, participation in health research

INTRODUCTION

Engaging American Indians in research has become an important challenge faced by investigators who hope to address disparities in health. Investigators who conduct research that involves under-served populations, especially American Indians, are acutely aware of the role of historical events and current experiences with medical care in contributing to distrust of medical research.[1] Researchers sensitive to these issues often view community-based participatory research (CBPR) as an approach that can help address some of these barriers.

Advocates of CBPR emphasize a number of key principles for conducting CBPR. Some of the key CBPR principles are promoting active collaboration and participation at every stage of research;[2–5] fostering co-learning between researchers and community residents;[4–8] establishing a mutually respectful partnership between researchers and community;[9] equitably involving all partners in all phases of research;[2,9] ensuring projects are community-driven;[3,5,6] building on strengths and resources within the community; disseminating results in useful terms;[2,4] ensuring research and intervention strategies are culturally appropriate;[3–5] defining community by the people whose health is most likely to be affected by the research;[2,4] employing community residents as research staff;[10] and integrating knowledge and action for the mutual benefit of all partners.[4,9] Researchers have strongly emphasized the importance of employing these principles with older minority subpopulations, especially American Indians.[11] However, to date, no systematic, empiric inquiries have been made into whether employing these principles might influence an American Indian's decision to participate in research.

Research plays a dominant role in establishing the benefits of specific interventions and procedures. Although investigators have tried to increase the representation of minorities in health research, especially in response to the 1993 National Institutes of Health requirement to include women and minorities,[12] the scientific progress embodied in the results of such research is not shared equitably among all segments of the American population. To

From the University of Colorado Health Sciences Center, American Indian and Alaska Native Programs, Aurora, Colorado (TDN, SMM, CC, JAH); Human Subjects Division (HM), and Department of Medicine (DB), University of Washington, Seattle, Washington; Black Hills Center for American Indian Health, Rapid City, South Dakota (JAH).

Address correspondence and reprint requests to Tim D. Noe, MDiv; University of Colorado Health Science Center, American Indian and Alaska Native Programs; Nighthorse Campbell Native Health Building, Mail Stop F800, PO Box 6508, Aurora, CO 80045-0508; 303-724-1446; 303-724-1461 (fax); timothy.noe@uchsc.edu

increase the proportion of racial and ethnic minorities in research, we must better understand potential participants' decision-making processes regarding participation in clinical and public health investigations.

Historically, few American Indians, especially elders, have taken part in research studies, and little has changed in the last decade. Notably, the Institute of Medicine has recently encouraged participation in research as one strategy to eliminate the health disparities experienced by American Indians.[13] However, little is known about the involvement of American Indians in health research,[14,15] and more specifically, whether employing CBPR principles will increase the likelihood of participation among individuals from underserved populations.

Employing a CBPR approach may prove to be successful in addressing several key obstacles to successfully engaging diverse groups in health research. These obstacles are the investigators' failure to gain trust and establish credibility with the population of interest and[14,16–19] ineffective communication of the study's rationale and relevance.[20–25]

Addressing negative perceptions among minority communities of research institutions may also be a key benefit to utilizing a CBPR approach.[21,26,27] Universities are often viewed as elitist and not committed to the welfare of minority communities,[28] not having adequate resources for effective outreach, lacking in support for investigators from diverse backgrounds, and supportive of policies for the conduct of research that are perceived as burdensome.[26] Furthermore, tensions between academic health centers and community health agencies may lead to assumptions that the benefits of research do not outweigh the costs to the community.[28] This is exacerbated by minority groups' limited access to health care provided in academic medical settings, thereby reducing opportunities to learn about and enroll in clinical studies.[21,28]

To address these gaps, we surveyed American Indians at three tribal colleges and universities (TCUs) on the Northern Plains to determine their likelihood of participation in research if CBPR principles were used. Although we have previously published the results of this study,[29] in this supplement we discuss findings on the extent to which respondent age, sex, education, cultural affiliation, tribal status, and prior experience with research may interact with the implementation of critical CBPR principles to increase or decrease the likelihood of participating in health research.

METHODS

Employing CBPR Principles

Not only did we seek to ascertain the extent to which CBPR principles affect the likelihood that American Indians will participate in health research, we also sought to employ a number of CBPR principles to design and implement the study. We have a longstanding research relationship with the targeted communities, and we fund field offices in two of the three communities. This study also addressed a question that the community felt was important. Many community members had expressed an interest in learning how to get more American Indians involved in health research in an effort to address serious health issues in the community. In addition, by conducting focus groups to provide consultation in the survey design and employing community members in the conduct of the data collection activities (ie, survey administration), we collaborated closely with the communities and maintained a culturally sensitive research infrastructure. Finally, we hired and worked closely with community-based liaisons throughout the entire research process.

Setting and Sample

As previously described,[29] we surveyed a convenience sample of all undergraduate and graduate students who were enrolling for formal academic coursework during scheduled registration periods at three rural, reservation-based, Northern Plains TCUs, each located on a different reservation. TCUs are comparable to historically Black colleges, and provide the major post-secondary educational opportunity for most AI students who live in reservation communities and are interested in associate- and baccalaureate-level education. Data collection occurred at site 1 during spring 2003, at site 2 during fall 2003, and at site 3 in spring 2004. The number of potential respondents was 400 students at site 1, 218 students at site 2, and 800 students at site 3.

A booth was set up in the registration area, and students were approached by project staff as they registered for classes. Potential respondents were informed that the purpose of the survey was to determine what factors influence participation in health research. Participants received a 60-minute phone card for completing the anonymous survey. On the basis of previous research experience in these communities, we anticipated a response rate $\geq$75%. The study was approved by each tribe and the university's institutional review board.

Study Vignettes

Survey development followed a number of key steps that reflect CBPR principles. The first step involved convening a group of 10 American Indian investigators in the context of a post-doctoral fellowship program. The investigators identified a number of potential vignettes (i.e., hypothetical research studies) which might capture factors that may influence an American Indian's decision regarding engaging in research activities.[29–31] These vignettes were discussed at length then questions were prepared that might be asked of

respondents regarding each hypothetical study. The questions were designed to elicit responses to key elements of CBPR and whether these elements might increase a respondent's likelihood of participation. The vignettes and questions were then compiled in a survey format.

To assess the impact of CBPR principles on respondents' likelihood of participating in research, each survey questionnaire asked about their willingness to participate in four hypothetical studies (vignettes): a focus group, an exploratory genetic study, a behavioral intervention, and a clinical drug trial. The vignettes that were employed in the survey are as follows.

Study 1

You are being asked to participate in a study about health in your community. This study will use group interview discussions, called ''focus groups,'' in which community members meet in groups of six to eight people to talk about issues. The focus group will take approximately two hours of your time. The questions in the focus group will include asking about your personal opinions and experiences.

Study 2

You are being invited to participate in a study to see if certain genes contribute to health. You will be interviewed about your health and asked to have a blood test. You will also be asked to give blood that will be used to find out whether you have certain types of genes. Researchers suspect that some of these genes may be involved in health. To see if this is true, researchers will compare the genes in people who have health problems with those who do not. Data collection for the study will take approximately two hours of your time.

Study 3

You are being invited to participate in a study testing how changes in behavior might affect your health and the health of your community. Half of the people who agree to participate in the study will be assigned to a new treatment that emphasizes changing their behavior. The other half will be in a group that only receives information about health. The treatment group will participate in five weekly two-hour support group sessions. After those first five weeks, there will be weekly followup sessions with an educator for an additional five weeks. The decision about who gets in the treatment group and who gets only the informational materials will be made randomly, as in flipping a coin. The study will require 10 sessions over a period of six months for all participants, totaling 15 hours of your time. All the study visits, treatments, and followup will be provided free of charge.

Study 4

You are being invited to participate in a study that is testing an experimental drug for a problem that is common in your community. This experimental drug may be better than anything on the market, but researchers need to complete this study to find out. People who agree to be in the study will get either the experimental drug or a drug that is currently approved. The decision about who gets the experimental drug and who gets the current drug will be made randomly, as in flipping a coin. The study will require 10 research visits over a period of six months. All the study visits, treatments and follow up will be provided free of charge.

After each vignette 33 questions were listed. The first question asked how likely the respondent would be to participate given just the information in the vignette. The respondents answered how likely they would be to participate by choosing a response category from 1 to 5, where 1 indicated ''I definitely would not'' and 5 indicated ''I definitely would.'' Then came 32 additional questions where each provided an additional piece of information about the study and asked again how likely the respondent would be to participate. The additional piece of information provided in each of these questions addressed CBPR principles such as: the nature of the research institution collaborating on the study; the extent of community involvement in developing the study, collecting data, and interpreting data; whether or not the study addressed a primary community concern; whether or not the results will benefit the community, the risks involved in the study; and how the results of the study are used to contribute to likelihood of participation. At the end of each questionnaire we collected data on sociodemographic background consisting of age, gender, marital status, education, whether respondents had children, and how many years they had lived in an urban area during their lives. The final survey took 20–25 minutes to complete

Focus Groups. The second step of survey development involved convening focus groups in each TCU community with the goal of reviewing the survey for cultural relevance and comprehensibility. Focus group work proceeded in five distinct steps: 1) working with TCUs administrators to identify, recruit, and hire a local TCU liaison, who was a tribal member and well-established in the community; 2) identifying and recruiting focus group members; 3) arranging for facilities and scheduling focus groups; 4) conducting focus group discussions, and 5) revising and finalizing the survey based on focus group feedback. Focus group discussions were audio-taped, transcribed, and supplemented by extensive staff notes. Recommendations were then used to revise the survey and finalize it prior to data collection at each site.

A total of 9 focus group members participated at Site 1. Of those, 67% were female. Seven volunteers participated in the Site 2 focus group; 58%

Table 1. Descriptive characteristics of respondents by site

	Total		Site 1		Site 2		Site 3	
	N=891–1031[1]		*N=258–306**		*N=170–208**		*N=463–517**	
	% or Mean	99% CI	% or Mean	99% CI	% or Mean	99% CI	% or Mean	99% CI
Mean age, years	33.6	32.7–34.6	32.7	30.9–34.4	36.5	34.1–38.8	33.1	31.8–34.4
Male, %	33.5	29.8–37.4	33.7	26.8–41.0	35.6	27.2–44.6	32.6	27.4–38.2
Racial/Ethnic Affiliation, %								
American Indian	92.1	89.6–94.1	94.4	90.2–97.3	90.9	84.5–95.3	91.1	87.4–94.0
White	9.6	7.4–12.2	10.5	6.4–15.8	9.1	4.7–15.5	9.4	6.3–13.1
Hispanic	2.4	1.4–4.0	2.3	.7–5.5	1.4	.2–5.2	2.9	1.3–5.4
Black	1.1	.4–2.2	.7	.03–3.0	1.0	.05–4.4	1.4	.4–3.3
Marital Status, %								
Never married	48.0	44.0–52.2	49.8	42.2–57.4	43.1	34.2–52.4	49.1	43.3–54.9
Married	26.6	23.1–30.3	26.3	20.0–33.4	27.5	19.8–36.2	26.4	21.5–31.8
Widowed	3.0	1.8–4.6	2.7	.9–6.1	4.9	1.9–10.2	2.4	1.0–4.7
Divorced	16.8	13.9–20.0	15.5	10.5–21.6	20.6	13.8–28.8	16.0	12.0–20.6
Separated	5.6	3.9–7.7	5.7	2.8–10.1	3.9	1.3–8.9	6.1	3.7–9.4
Have Children, %	73.9	70.2–77.3	70.3	63.1–76.9	77.2	68.8–84.3	74.7	69.4–79.5
Education, %								
High school graduate or less	23.2	19.9–26.8	29.2	22.7–36.3	29.8	22.0–38.6	17.0	13.0–21.7
Some college but no degree	45.5	41.5–49.6	45.9	38.5–53.4	37.5	29.0–46.6	48.6	42.8–54.3
Associate or higher degree	31.3	27.6–35.1	24.9	18.8–31.8	32.7	24.6–41.6	34.4	29.1–40.0
Residence, mean years								
Lived on or near a reservation	22.9	21.8–24.1	23.1	21.0–25.3	26.2	23.2–29.1	21.6	20.1–23.1
Lived in an urban area	16.0	14.8–17.2	17.6	15.2–19.9	16.8	13.6–20.0	15.1	13.6–16.6
Ever Worked in Health Care, %	29.4	25.8–33.2	28.0	21.6–35.2	33.3	25.1–42.3	28.6	23.6–34.1
Ever Been in Research Study, %	31.0	27.3–34.8	29.8	23.2–37.0	17.9	11.6–25.7	36.9	31.5–42.6

* *N* based on variances in characteristic and amount of missing data; CI = confidence interval.

were female. At Site 3, 10 members participated, with 62% female.

Focus groups provided significant feedback which was subsequently incorporated into the survey design. Typical focus group feedback included revision of language to increase respondent comprehension (e.g., changing ''scenario'' to ''situation'') formatting changes to decrease respondent confusion and wording changes to increase cultural sensitivity (e.g., de-emphasizing potential conflict by changing ''problem'' to ''issue''). In addition, focus groups members believed it would be important to ask respondents to imagine they were being asked to participate in each scenario, so the preamble to each scenario was modified to include ''imagine you are being asked to participate…''

Analysis

The initial step in the analysis involved creating 4 datasets, one for each survey scenario, by pooling data from each of the 3 TCU sites. Next, for each hypothetical scenario, we calculated the percentages of respondents having different demographic characteristics and probabilities of participation. Finally, logistic regressions were calculated to determine how employing CBPR principles in each hypothetical scenario might influence the respondents' likelihood of participation.

In the logistic regression analysis the datasets were constructed to have 33 observations for each respondent, one observation for each of the questions that followed each vignette. The key independent variables in the logistic regressions were 33 dummy (1/0) variables corresponding to these questions. The first observation for each respondent had values of 0 for all of these dummy variables to indicate that no additional information about the study had been supplied. On the other observations just one of these variables had a value of ''1'' to show which *additional* piece of information about the study had been had been provided in the question. Other control independent variables indicated each respondent's demographic characteristics and where they went to school (site 1, 2, or 3). The dependent variable indicated the respondent's likelihood of participation in response to the question represented by the observation. Values of the dependent variable were coded so that ''1'' indicated that the respondent said s/he probably or definitely would participate given the additional information about the study, and ''0'' denoted that the respondent answered that s/he ''was not sure, probably would not participate or definitely would not participate.''

The logistic regressions were run using Stata.[30] Because the values of the dependent variable were correlated across observations, the logistic regressions were population average models

Table 2. Odds ratios and confidence intervals for influences on research participation by study type

Respondent Characteristics	Focus Group OR (99%CI)	Genetic Study OR (99%CI)	Intervention OR (99%CI)	Drug Study OR (99%CI)
Site 2	1.0* –	1.0* –	1.0* –	1.0* –
Site 1	.8 (.6–1.1)	.9 (.7–1.4)	.9 (.6–1.3)	1.4 (1.0–2.2)†
Site 3	.9 (.7–1.2)	.9 (.6–1.3)	.9 (.7–1.3)	1.4 (1.0–2.1)†
Age	1.1 (1.0–1.1)†	1.1 (1.0–1.2)†	1.1 (1.0–1.2)†	1.0 (.9–1.1)
Male	.9 (.7–1.1)	.9 (.7–1.1)	.9 (.7–1.2)	1.3 (1.0–1.8)†
American Indian race/tribal affiliation	1.0 (.7–1.6)	1.0 (.6–1.7)	1.4 (.8–2.4)	1.2 (.7–2.1)
Never married	1.0* –	1.0* –	1.0* –	1.0* –
Married/cohabitating	.9 (.7–1.1)	1.0 (.7–1.3)	1.1 (.8–1.4)	1.0 (.7–1.3)
Widowed/divorced/separated	1.0 (.8–1.3)	1.0 (.7–1.3)	1.1 (.8–1.5)	1.0 (.7–1.5)
High school or less education	1.0	1.0	1.0	1.0
Some college but no degree	1.0 (.8–1.4)	.9 (.7–1.3)	1.0 (.7–1.4)	.8 (.6–1.1)
Associate or higher college degree	1.0 (.7–1.4)	.8 (.5–1.1)	1.0 (.7–1.5)	.6 0(.4–1.0)††
Years lived on reservation	1.0 (1.0–1.0)	1.0 (1.0–1.0)	1.0 (1.0–1.0)	1.0 (1.0–1.0)
Has children	1.0 (.8–1.3)	1.0 (.7–1.4)	.9 (.6–1.2)	.9 (.6–1.3)
Been in a research study	1.1 (.8–1.4)	1.1 (.8–1.5)	1.1 (.9–1.5)	1.1 (.8–1.5)
Worked in health care	1.1 (.9–1.4)	1.2 (.9–1.6)	1.1 (.8–1.5)	1.0 (.7–1.4)
Research Institution				
State university	1.4 (1.1–1.7)§	.7 (.6–.8)§	.8 (.7–1.0)††	.9 (.8–1.0)†
Tribal college or university	2.4 (1.9–3.0)§	1.3 (1.0–1.5)§	1.3 (1.1–1.5)§	‖
Federal government	.4 (.3–.5)§	.4 (.3–.5)§	.5 (.4–.6)§	¶
Private healthcare provider	.9 (.7–1.1)	.8 (.7–1.0)††	.9 (.7–1.0)†	1.1 (.9–1.2)
Tribal government	.9 (.7–1.1)	.7 (.5–.8)§	.8 (.7–1.0)††	**
National organization	2.4 (1.8–3.0)§	1.7 (1.4–2.1)§	1.8 (1.5–2.1)§	††
Office run by researchers	.9 (.7–1.2)	.7 (.6–.8)§	.9 (.7–1.0)[2]	1.0 (.8–1.1)
Community Involvement				
Developing study	1.8 (1.4–2.2)§	1.0 (.8–1.2)	1.2 (1.0–1.4)††	1.3 (1.1–1.5)§
Collecting data	1.6 (1.3–2.0)§	.8 (.7–1.0)††	1.1 (.9–1.3)††	1.3 (1.1–1.5)§
Interpreting data	1.3 (1.0–1.6)††	1.0 (.8–1.2)	1.2 (1.0–1.5)††	1.4 (1.1–1.6)§
Researcher is American Indian	3.3 (2.5–4.3)§	1.5 (1.3–1.9)§	1.7 (1.4–2.1)§	1.7 (1.5–2.0)§
Salience				
Personal experience with topic	2.1 (1.6–2.7)§	1.5 (1.2–1.8)§	1.5 (1.2–1.8)§	1.6 (1.4–1.9)§
Addresses serious community problem	4.0 (3.0–5.4)§	1.9 (1.6–2.4)§	2.2 (1.8–2.7)§	2.0 (1.6–2.3)§
Research brings money to community	4.1 (3.0–5.4)§	2.2 (1.8–2.7)§	2.4 (1.9–3.0)§	2.3 (1.9–2.7)§
Study about lactose intolerance	1.2 (1.0–1.6)†	1.1 (.9–1.3)	1.3 (1.1–1.6)††	1.8 (1.5–2.1)§
Study about cancer	3.3 (2.5–4.4)§	2.3 (1.8–2.9)§	2.5 (2.0–3.1)§	3.0 (2.5–3.6)§
Study about diabetes	4.6 (3.4–6.3)§	2.7 (2.1–3.4)§	2.9 (2.3–3.6)§	3.2 (2.6–3.9)§
Study about depression	3.0 (2.3–3.9)§	2.2 (1.7–2.7)§	2.4 (2.0–3.0)§	2.8 (2.3–3.4)§
Study about alcoholism	3.2 (2.4–4.2)§	2.2 (1.7–2.7)§	2.5 (2.0–3.1)§	2.8 (2.3–3.4)§
Compensation/Benefits				
Study leads to new treatment/service	3.0 (2.3–3.9)§	2.3 (1.9–2.9)§	2.2 (1.8–2.7)§	2.3 (1.9–2.7)§
No compensation	.8 (.6–1.0)†	.7 (.5–.8)§	.8 (.6–.9)§	.8 (.7–1.0)†
Immediate compensation	2.3 (1.7–2.9)§	.7 (.5–.8)§	1.9 (1.5–2.3)§	.8 (.7–1.0)†
Feedback about results	1.6 (1.2–2.0)§	1.4 (1.1–1.7)§	1.5 (1.2–1.8)§	1.7 (1.4–2.0)§
Risks				
Risk of physical harm	0.1 (0.1–0.2)§	0.1 (0.1–1.2)§	0.2 (0.1–0.2)§	0.2 (0.1–0.2)§
Risk of emotional harm	0.1 (0.1–0.2)§	0.1 (0.1–0.2)§	0.1 (0.1–0.2)§	0.2 (0.1–0.3)§
Results discriminate against family	0.1 (0.0–0.1)§	0.1 (0.0–0.1)§	0.1 (0.1–0.1)§	0.2 (0.1–0.2)§
Results discriminate against tribe/race	0.1 (0.0–0.1)§	0.1 (0.0–0.1)§	0.1 (0.1–0.1)§	0.2 (0.1–0.2)§
Information Use				
Risk of broken confidentiality	0.1 (0.0–0.1)§	0.1 (0.0–0.1)§	0.1 (0.1–0.1)§	0.2 (0.1–0.2)§
Data anonymous	2.1 (1.6–2.6)§	1.0 (0.9–1.3)	1.1 (0.9–1.3)	1.1 (0.9–1.4)
Researchers use medical records	0.3 (0.2–0.4)§	0.3 (0.2–0.4)§	0.4 (0.3–0.5)§	0.6 (0.5–0.7)§
Data only used for specific problem	0.6 (0.5–0.8)§	0.6 (0.5–0.8)§	0.8 (0.7–1.0)††	0.9 (0.8–1.1)
Data used to answer new questions	1.2 (0.9–1.5)	1.0 (0.9–1.3)	1.2 (1.0–1.4)†	‡‡

OR = odds ratio; CI = confidence interval.

Table 2. Continued

Note. Data from Tables 1 and 2 are from Noe, T., Manson, S.M., Croy, C., McGough, H., Henderson, J. and Buchwald, D. (2006). In their Own Voices: American Indian Decisions to Participate in Health Research. In Trimble, J. and Fisher, C. (Eds.) *The Handbook of Ethical Research with Ethnocultural Populations and Communities*. Thousand Oaks: Sage Publications; pp. 77–92. Reprinted with permission.

* This category was the reference group;

† Odds ratio differs from 1.0 at $P<.05$;

‡ Odds ratio differs from 1.0 at $P<.01$;

§ Odds ratio differs from 1.0 at $P<.001$;

Note. Odds ratios are reported in the table when there was no statistical evidence that they varied across the data collection sites (item interactions with site were not statistically significant at $p < .05$). Occasionally, the odds ratio between an item and participation in the drug study varied across the sites (interaction with site was statistically significant). In those instances we report the odds ratios and confidence interval for the item at each individual site in the following notes

‖ Site 1 [1.2 (1.0–1.6)]†; Site 2 [1.4 (1.1–1.9)]††; Site 3 [1.1 (.9–1.3)]

¶ Site 1 [0.8 (.6–1.0)]†; Site 2 [0.8 (.6–1.2)]; Site 3 [0.6 (.4–.7)]§

** Site 1 [0.8 (.6–1.1); Site 2 [1.2 (.9–1.6); Site 3 [0.7 (.6–.9)]§;

†† Site 1 [1.6 (1.2–2.0)]§; Site 2 [2.2 (1.7–2.9)]§; Site 3 [1.6 (1.3–2.0)]§;

‡‡ Site 1 [1.5 (1.2–2.0)]§; Site 2 [1.1 (0.8–1.5)]; Site 3 [1.3 (1.1–1.6)]††

Note. Upper and lower limits of CI may round to appear the same as OR.

for correlated data. As discussed by Hosmer and Lemeshow[31] this modeling approach adjusts the standard errors of the logistic regression coefficients to reflect correlations within clusters. The independent variables that indicated the piece of additional information given in the questions were cluster-specific covariates because their values varied across observations within the cluster for each respondent. The values of the demographic independent variables did not vary across observations within each respondent cluster. In the logistic regressions potential interactions were examined between the site variable and respondent characteristics, type of research institution, community involvement, salience, compensation/benefits, and information use. We also tested 3 interactions with age: age x years lived on the reservation, age x previous participation in research, and age x having children. To determine whether the coefficients were significantly different from "0" we examined the *P* values of the Z scores for the coefficients in the Stata output. To judge whether the odds ratios (ORs) varied across the scenarios, their 99% confidence intervals were checked for overlap.

RESULTS

Based on previous experience, we anticipated a response rate of approximately 75%. The average response rate across all sites was 82% (Site 1 = 80%, Site 2 = 100%, and Site 3 = 66%) which exceeded our expectations. Table 1 provides a summary of the demographic and social characteristics of the sample respondents. The mean age was 33.6 with 66.5% being female. Ninety-two percent of the students were American Indian with 11.7% over the age of 50. Twenty-six percent were married. The respondents were primarily rural residents, having spent on average almost 23 years living on or near a reservation. Almost one-third had previously participated in research studies.

Respondent Characteristics

Table 2 presents the odds of research participation by study type based upon respondent characteristics, research institution conducting the study, community involvement in the study, salience of the study, compensation/benefits of the study, risk, and how information from the study will be used. Generally, the characteristics of the respondents did not significantly influence the odds of participating in the 4 hypothetical studies based solely on the information provided in the vignettes. However, Site 1 and Site 3 respondents were more likely to participate in the drug study than respondents from Site 2. Also, the odds of participation increased by a factor of 1.1 for every year of age for the focus group, genetic, and behavior intervention vignettes. Respondents with an associate or higher degree were less likely to participate in the drug study than were people with only a high school or less education. No significant interactions were detected with age, and the interactions with site are noted at the bottom of Table 2.

Research Institution

The type of institution that is conducting the research had a significant impact on respondents' likelihood of participation. Studies conducted by a tribal college or university increased the odds of participation for all 4 hypothetical studies with the exception of the drug study at Site 3. These factors had a significantly greater positive effect for the focus group vignette. Similarly, a study conducted by a national organization (e.g., the American Diabetes Association, or American Cancer Society) increased the odds of participation for all studies. In contrast, if the study was conducted by the federal government the likelihood of participation decreased across all types of studies with the exception of the drug study at Site 2.

Community Involvement

As can be seen in Table 2, community involvement in developing a study and having an American Indian as the lead researcher substantially increased likelihood of participation for almost all

of the hypothetical studies. The notable exception was for the genetic study. Community involvement in data collection actually decreased the odds of participation in the genetic study. Also, community involvement in developing the study was not significant for the genetic study.

Salience

Questions related to salience sought to capture the relevance of the study's substantive focus to the community, a key CBPR principle. The results demonstrated that salience had a dramatic impact on likelihood of participation. Indeed, factors associated with salience increased the odds of participation more than any other element of study design. The largest odds ratios were observed when the research addressed a serious problem in the community, or the research could bring money to their community, or the study was about cancer, diabetes, depression, or alcoholism.

Compensation, Benefits, and Risk

Likelihood of participation also increased if the study was perceived to provide a significant benefit. If new treatments or services might emerge from the research, the odds of participation were significantly higher for all research scenarios. Immediate compensation also increased participation in the focus group and intervention vignettes. Conversely, perceived risks decreased the odds of participation more than any other design element. Potential physical and emotional harm, as well as possible personal or racial discrimination, precipitated dramatic declines in likely participation in all hypothetical studies.

Information Use

How the information gathered from the study will be used also significantly impacted likelihood of participation in research studies. If there was a risk that confidentiality might be compromised likelihood of participation significantly decreased for all vignettes. This possibility was among the most potent factors that decreased participation. Conversely, however, keeping information anonymous increased the likelihood of participation only in the focus group study. Additionally, using study results to answer new, future questions increased likelihood of participation for the intervention study and the drug study but only for Sites 1 and Site 3.

DISCUSSION

We hypothesized that employing a CBPR approach may be successful in addressing several key obstacles to successfully engaging diverse groups in health research. These obstacles are: the investigators' failure to gain trust and establish credibility with the population of interest; ineffective communication of the study's rationale and relevance, and investigator biases. In this regard, we found that research led by an American Indian investigator significantly increased the odds of participation across all four types of studies. Likewise, the salience of the research strongly and positively increased participation. For example, if respondents perceived the research would address a serious problem in their community, such as diabetes or cancer, or if the study would bring money into the community, the odds of participating increased markedly.

Given the negative perceptions of research institutions among minority communities, we hypothesized that the type of institution collaborating with the community to conduct the research may also affect the likelihood of participating. We observed that the type of institution conducting the hypothetical studies significantly affected the likelihood of participation among our respondents. Studies conducted by TCUs or national organizations generally increased participation significantly across all four hypothetical studies, but not for site 3. Conversely, if the study was conducted by the federal government, the odds of participation generally decreased, except at site 2. However, our survey did not investigate the mitigating effects of employing CBPR principles upon the negative perceptions of research institutions. We only inquired about the likelihood of participating on the basis of the type of institution involved in conducting the research. Further investigation is needed to determine if employing CBPR principles will reduce negative perceptions.

The most important principles of the CBPR approach with minority communities emphasize the benefits of equitably involving all partners in all phases of research. These efforts embrace the key principles of community involvement in developing the study, collecting data, and interpreting data. Thus, we hypothesized that community involvement in all aspects of the study would have a significant impact upon likelihood of participation in research. In our study, engaging the community in developing the study and collecting the data generally increased the odds of participation, as did involving them in understanding the results. The only exception was for the genetic study for the factors of community involvement in developing the study and collecting the data, which did not significantly increase the odds of participation.

Another key principle of the CBPR approach is ensuring that the study addresses a primary community concern, not just the concern of the researchers. Therefore, we hypothesized that if the research is viewed as addressing a primary concern of the community, the likelihood of participation in the research will increase. Results from our study indicate that participation was positively influenced if the information from the study would be used in the future to answer new questions (only

significant for the intervention study and the drug study for sites 1 and 3).

Community-based participatory research (CBPR) also places emphasis on the principle that the results of research must benefit the community. Consequently, we hypothesized that if the research is viewed as benefiting the community, the likelihood of participation in the research will increase. In our study, the likelihood of participation increased if the study addressed a serious problem in the community and if it brought money to the community. In addition, for all scenarios, the odds of participation were significantly higher if new treatments or services might emerge from the research.

One benefit of a CBPR approach is the opportunity for the community to work closely with the researcher to ensure that the risks involved in the study are minimal. We hypothesized that if potential risks of the research are perceived as minimal, the likelihood of participation in the research will increase. Our results indicate that perceived risks decreased the odds of participation more than any other design element. Potential physical and emotional harm, as well as possible personal or racial discrimination, resulted in dramatic declines in likely participation in all of the hypothetical studies. In addition, risk that confidentiality might be broken significantly decreased participation for all vignettes.

We also hypothesized that involving minority researchers would increase the odds of participation by ensuring the research and intervention strategies are more culturally appropriate, a key CBPR principle. In our study, having an American Indian as the lead researcher substantially increased the likelihood of participation for all hypothetical research situations.

Although this study has provided key insights into whether employing CBPR principles in research design and implementation increase the likelihood of participation of AIs in health research, this study is not without several limitations. Sampling the student population of the tribal colleges and universities undoubtedly over-represented younger, more educated members of the local community. However, the respondents in the sample were older (mean age = 34), than those typically found in other institutions of higher education.[32] In addition, only 3 closely related tribes were included in this study. Given these limitations, our findings, despite being from among the largest of tribes, cannot be generalized to the entire AI population, the non-student local community, older individuals, or urban AI populations. Finally, vignette-based research is a well established and accepted form of qualitative research.[33,34] However, it has not been widely used in quantitative studies. Our use of vignettes may not have adequately captured all of the relevant constructs, especially given the brevity of our survey.

This study represents the first large-scale, systematic inquiry into whether employing a CBPR approach affects the participation of AIs in health research. Although the CBPR literature has provided important insights into the broader principles that influence the research process, we have, until now, lacked empirical corroboration of whether these principles affect participation of underserved communities in health research. Our findings document key factors influencing study participation, thereby identifying approaches that might increase participation of AIs in health research. Close attention to the use of CBPR principles such as cultural sensitivity, community involvement, potential risks and benefits of research, and how results will be used, are essential elements in conceptualizing, designing, and implementing successful health research efforts in partnership with AI populations.

ACKNOWLEDGMENTS

The preparation of this manuscript was supported by U26 94 00002 (J.A. Henderson, principal investigator), P30 AG15292 (S.M. Manson, principal investigator), P01 MH 42473 (S.M. Manson, principal investigator), P01 HS10854 (S.M. Manson, principal investigator), and P60 MD000507 (S.M. Manson, principal investigator).

REFERENCES

1. Ammerman A, Corbie-Smith G, StGeorge DM, Washington C, Weathers B, Jackson-Christian B. Research expectations among African American church leaders in the PRAISE Project: a randomized trial guided by community-based participatory research. *Am J Public Health*. 2003;93(10):1720–1727.
2. O'Fallon LR, Dearry A. Community-based participatory research as a tool to advance environmental sciences. *Environ Health Perspect*. 2002;110(Suppl 2):155–159.
3. Freudenberg N. Health promotion in the city: a review of current and future prospects in the United States. *Ann Rev Public Health*. 2000; 21:473–503.
4. Israel BA, Schultz AJ, Parker EA, Becker AB. Review of community-based research: assessing partnership approaches to improve public health. *Ann Rev Public Health*. 1998;19: 173–202.
5. Wallerstein N. Power between evaluator and community: research relationships with New Mexico's healthier communities. *Soc Sci Med*. 1999;49:39–53.
6. Evans SM, Birchenough AC, Fletcher H. The value and validity of community-based research: TBT contamination of the North Sea. *Mar Pollut Bull*. 2000;40(3):220–225.
7. Davis SM, Ried R. Practicing participatory research in American Indian communities. *Am J Nutr*. 1999;69(Suppl):755s–759s.
8. Green LW. Health education's contributions to public health in the twentieth century: a glimpse through public health promotion's rear window. *Ann Rev Public Health*. 1999;20: 67–88.
9. Adams A, Miller-Korth N, Brown D. Learning to work together: developing academic and community partnerships. *Wis Med J*. 2004; 103(2):15–19.
10. McAllister CL, Green BL, Terry MA, Herman V, Mulvey L. Parents, practitioners, and researchers: community-based participatory research with early head start. *Am J Public Health*. 2003;93(10):1672–1679.
11. Moreno-John G, Gachie A, Fleming C, et al. Ethnic minority older adults participating in clinical research. *J Aging Health*. 2004; 15(Suppl 5):93s–123s.
12. Hohmann AA, Parron L. How the new guidlelines on inclusion of women and minorities apply: efficacy trials, effectiveness

trials, and valifity. *J Consult Clin Psychol*. 1996; 64(5):851–55.
13. Institute of Medicine. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington: National Academy Press; 2002. p. 235–243.
14. Manson SM, Garroutte EM, Goins RT, Henderson P. Access, relevance, and control in the research process: lessons from Indian country. *J Aging Health*. 2004;16:58s–77s.
15. Macaulay AC, Commanda LA, Freeman WL, et al. Participatory research maximizes community and lay involvement. *BMJ*. 1999;319: 774–778.
16. Areán P, Gallagher-Thompson D. Issues and recommendations for the recruitment and retention of older ethnic minority adults into clinical research. *J Consult Clin Psychol*. 1996; 64:875–880.
17. Whelton PK, Lee JY, Kusek JW, et al. Recruitment experience in the African American Study of Kidney Disease and Hypertension (AASK) pilot study. *Control Clin Trials*. 1996;16(Suppl):17S–33S.
18. Norton IM, Manson SM. Research in American Indian and Alaska Native communities: navigating the cultural universe of values and process. *J Consult Clin Psychol*. 1996;64: 856–860.
19. Corbie-Smith G, Thomas S, Williams M, Moody-Acres S. Attitudes and beliefs of African Americans toward participation in medical research. *J Gen Intern Med*. 1999;14: 537–546.
20. Levkoff S, Levy B, Weitzman P. The matching model of recruitment. *J Mental Health Aging*. 2000;6:29–38.
21. Shavers V, Lynch C, Burmeister L. Racial differences in factors that influence the willingness to participate in medical research studies. *Ann Epidemiol*. 2002;12:248–256.
22. Brawley O, Tejedam H. Minority inclusion in clinical trials issues and potential strategies. *J Natl Cancer Inst*. 1995;17:55–57.
23. Gavaghan H. Clinical trials face lack of minority group volunteers. *Nature*. 1995;373: 178–187.
24. Lewis CE, George V, Fouad M, et al. Recruitment strategies in the Women's Health Trial: feasibility study in minority populations. *Control Clin Trials*. 1998;19:461–476.
25. Swanson G, Ward A. Recruiting minorities into clinical trials: toward a participant-friendly system. *J Natl Cancer Inst*. 1995;87: 1747–1759.
26. Unson C, Dunbar N, Curry L, et al. The effects of knowledge, attitudes, and significant others on decisions to enroll in a clinical trial on osteoporosis: implications for recruitment of older African-American women. *J Natl Med Assoc*. 2001;93:392–401.
27. Gorelick PB, Harris Y, Burnett B, et al. The recruitment triangle: reasons why African Americans enroll, refuse to enroll, or voluntarily withdraw from a clinical trial. *J Natl Med Assoc*. 1998;90:141–145.
28. Curry L, Jackson J. Recruitment and retention of diverse ethnic and racial groups in health research: an evolving science. In: Curry L, Jackson J, eds. *The Science of Inclusion: Recruiting and Retaining Racial and Ethnic Elders in Health Research*. Washington: Gerontological Society of America; 2003. p. 1–7.
29. Noe T, Manson SM, Croy C, McGough H, Henderson J, Buchwald D. In their Own Voices: American Indian Decisions to Participate in Health Research. In: Trimble J, Fisher C, eds. *The Handbook of Ethical Research with Ethnocultural Populations and Communities*. Thousand Oaks: Sage Publications; 2006:77–92.
30. StataCorp. *Stata Statistical Software: Release 8.0*. College Station, TX: Stata Corporation; 2003.
31. Hosmer DW, Lemeshow S. *Applied Logistic Regression*. New York, NY: John Wiley & Sons Inc; 2000:308–330.
32. National Center on Education Statistics. *Enrollment in public secondary education 1999–2000*. Washington, D.C; 2000:252.
33. Hughes R. Considering the Vignette Technique and its Application to a Study of Drug Injecting and HIV Risk and Safer behavior. *Sociology of Health and Illness*. 1998;20(3): 381–400.
34. Finch J. The vignette technique in survey research. *Sociology*. 1987;21:105–14.

AUTHOR CONTRIBUTION

Design concept of study: Noe, Manson, McGough
Acquisition of data: Noe, Manson, McGough, Henderson
Data analysis and interpretation: Noe, Manson, Croy, Buchwald, Henderson
Manuscript draft: Noe, Manson, Croy, Buchwald, McGough, Henderson
Statistical expertise: Noe, Manson, Croy
Acquisition of funding: Noe, Manson, Henderson
Administrative, technical, or material assistance: Noe, Manson
Supervision: Manson