Attitudes of Urban American Indians and Alaska Natives Regarding Participation in Research

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OBJECTIVE: To determine what factors influence participation in health research among American Indians and Alaska Natives.

METHODS: Using vignettes that described 3 types of research studies (a behavioral intervention trial, a genetic association study, and a pharmacotherapy trial), we surveyed 319 patients and 101 staff from an urban Indian health care facility to ascertain how study design, institutional sponsorship, community involvement, human subjects' issues, and subject matter influence participation.

RESULTS: Overall response rates were 93% for patients and 75% for staff. Hypothetical participation was highest for the genetic study (patients=64%; staff=48%), followed by the behavioral intervention (patients=46%; staff=42%), and the pharmacotherapy trial (patients=32%; staff=23%). The odds of participation (odds ratio [OR]) were generally increased among patients and staff when the study was conducted by health care providers (OR=1.3 to 2.9) and addressed serious health problems (OR=1.2 to 7.2), but were decreased if the federal government led the study (OR=0.3 to 0.5), confidentiality might be broken (OR=0.1 to 0.3), and compensation was not provided (OR=0.5 to 0.7).

CONCLUSION: Close attention to study type, institutional sponsorship, community involvement, potential risks and benefits, and topic are essential to conceptualizing, designing, and implementing successful health research with American Indian and Alaska Native populations.

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A growing body of literature documents problems in the recruitment and retention of minorities into studies of health, especially in the context of NIH requirements to include women and diverse populations in federally sponsored research.[1–13] Some clinical trials have achieved notable success with creative recruitment strategies in African-American and Latino communities,[14–19] but adequate information on factors that influence participation in research is only now emerging.[20] Although American Indian and Alaska Native (AI/AN) communities have often been at the forefront of debates about community control of, and involvement in, research,[21] virtually no publications exist on their attitudes regarding participation in research. In the single prior study that included AI/ANs, potential subjects knew little about cancer clinical trials and had no opportunity to participate.[22] They believed that participation in clinical trials could be beneficial, yet expressed a "mistrust of white people" and concerns about being treated like "guinea pigs."

In parallel with our work with reservation-based AI/AN students[23] we surveyed patients and staff from an urban multitribal Indian health care facility to examine the extent to which personal attributes, prior research experience, study sponsors, subject matter, and study design influenced participation in hypothetical studies.

METHODS

Clinical Setting and Population

This study was conducted among patients and employees of the Seattle Indian Health Board, which provides diverse medical, mental health, dental, preventive, and educational services to more than 6,500 of the 20,000 AI/ANs living in the greater Seattle area. It serves members of approximately 250 tribes who make more than 40,000 visits per year. More than a third of patients are at least 45 years of age, at least half are unemployed, 74% have incomes under the federally determined "poverty line," and 46% of medical and 72% of dental visits were provided for uninsured patients.

Vignette Survey

The vignettes used in this study asked respondents first about their willingness to participate in 3 generic protocols: a behavioral intervention, a genetic study, and a clinical drug trial. These study designs were selected because they represented fundamentally different types of involvement in research. The initial question on likelihood of participating in the study vignette was then followed by 10 questions designed to assess the degree to which the research institution's identity, the type of community involvement, the risk and benefits, and the subject under investigation contributed to the likelihood of participation. After reading the additional information on the study provided by each question, respondents again indicated how likely they were to participate given the new information. We also collected data on participants' demographic characteristics and, at the end of the survey, respondents were asked to list the health areas of greatest concern in their community. The final instrument was written at the eighth grade level and required about 15 minutes to complete (Table 1).

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Table 1. Characteristics of Respondents

	Patients $n = 319^*$	Staff $n = 101^*$
Demographics and experience		
Female, %	65	74
Age, mean y	39	43
Education, %		
High school graduate or less	43	13
Some college	46	53
Bachelor's degree or higher	11	34
Marital status, %		
Married	20	36
Widowed/divorced/separated	41	29
Never married	39	35
Have children, %	74	69
Urban residence, mean years	28	34
Ever participated in research, %	26	37
Research participation		
Vignette 1. Behavioral intervention, %		
Personally†	46	42
Would allow teenager‡	47	43
Vignette 2. Genetic study, %		
Personally	64	48
Would allow teenager	59	42
Vignette 3. Clinical drug trial, %		
Personally	32	23
Would allow teenager	24	15

**Two to 21 responses may be missing.*
†Percentage of respondents who would probably or definitely participate.
‡Percentage of respondents who would probably or definitely allow their teenage son or daughter to participate.

Data Collection

Patients served by the Seattle Indian Health Board share a single waiting room. All AI/ANs who were at least 18 years of age with appointments in the medical, dental, and mental heath counseling clinics, as well as those being seen by the alcohol, community health, or WIC programs, were approached on the days when the data collector was present. All data were collected by 1 individual to minimize the possibility of duplicate participants in this anonymous survey. Data were collected from June through August 2002 during weekday morning and afternoon clinic sessions. Questionnaires were also distributed to the staff of the Seattle Indian Health Board. The study was approved by the institutional review boards of the senior author and the Seattle Indian Health Board.

Statistical Analysis

The data were pooled to comprise 3 datasets, 1 for each vignette. We used logistic regressions to determine how the attributes of the hypothetical studies influenced a respondent's likelihood of participation. Each observation represented an answer to 1 of the 11 questions about the respondent's likelihood of participation for a specific vignette. The dependent variable for each observation was a variable wherein "1" indicated that the respondent said s/he would either probably or definitely participate given the additional information about the study and "0" denoted that the respondent did not choose either of these responses. The independent variables were coded "1" or "0" to indicate which piece of additional information had been read by the respondent; the respondent's demographic background data were also coded as 1/0.

Logistic regressions were population average models for correlated data because the values of the dependent variable were correlated across observations. This modeling approach adjusts the standard errors of the logistic regression coefficients to reflect correlations within clusters of answers from the same respondent.[24] Demographic information was included in the models to control for potential confounding. To judge whether the odds ratios varied across the scenarios, the 95% confidence intervals were examined for overlap. The Stata software xtgee command with the family (binomial), link (logit), corr(ind), and robust options was used to run the regressions.[25]

RESULTS

Demographics and Participation

A total of 319 eligible AI/AN patients and 101 staff completed the survey, representing response rates of 93% and 75%, respectively. When presented only with the information in the vignettes, participation rates were highest for the genetic study among both patients and staff. The behavioral intervention study attracted an intermediate number of patients and staff, while the clinical drug trial had the lowest rates of participation.

Influence of Study Characteristics on Participation

As shown in Table 2, research conducted by a health care provider increased the odds of participation for all 3 hypothetical studies, particularly among the patients. Conversely, studies conducted by the federal government consistently and dramatically decreased the patients' and staff's participation in all 3 studies. Community involvement increased the odds of participation among patients and staff only for the behavioral intervention, but involving the community in interpreting the results of the genetic research study significantly decreased the odds of participation for patients. A risk that confidentiality might be broken always significantly decreased both groups' participation, and not being paid decreased the odds of patient participation. Finally, the salience of the study's substantive focus to the community generally strongly influenced participation. Coding of the participants' open-ended question concerning the key health concerns in their communities mirrored these findings. Among those providing a write-in response, the most pressing concerns for both patients and staff were related to alcohol and drugs (patients=33%; staff=27%), and diabetes (patients=16%; staff=17%).

CONCLUSIONS

Obstacles to successfully engaging diverse groups in health research have been associated with investigator biases; investigators' failure to gain trust and establish credibility with the population of interest; and perceptions of sponsoring institutions.[26–33] In addition, universities are often viewed as elitist and not commited to the welfare of minority communities[2]; this perception is exacerbated by minority groups' limited access to academic medical settings, thereby reducing opportunities to learn about clinical studies.[31] Consistent with this literature, we observed that the type of institution conducting

Table 2. Odds of Participating in Research Derived from Logistic Regression Models

	OR	Patients (95% CI)	*P*	OR	Staff (95% CI)	*P*
Vignette 1. Behavioral Intervention Study		*n* =3,169*			*n* =1,023*	
Conducted by state university	1.4	1.1 to 1.8	.009	1.5	1.1 to 2.2	.03
Conducted by federal government	0.5	0.4 to 0.7	<.001	0.5	0.3 to 0.8	.006
Conducted by health care provider	2.9	2.3 to 3.8	<.001	2.0	1.4 to 2.9	<.001
Community involved in developing study	1.6	1.2 to 2.2	.001	1.6	1.1 to 2.5	.02
Community involved in collecting data	1.5	1.1 to 1.9	.007	1.6	1.0 to 2.6	.03
Community involved in interpreting results	1.5	1.1 to 2.0	.005	1.4	0.9 to 2.2	.19
Risk that confidentiality might be broken	0.2	0.1 to 0.2)	<.001	0.1	0.1 to 0.3	<.001
Participants will not be paid	0.7	0.5 to 0.9	.002	0.8	0.5 to 1.2	.27
Study is about diabetes	2.6	1.9 to 3.6	<.001	7.2	4.0 to 12.7	<.001
Study is about alcoholism	2.6	1.9 to 3.5	<.001	1.7	1.1 to 2.7	.02
Vignette 2. Genetics Study		*n* =3,135*			*n* =1,033*	
Conducted by state university	1.0	0.8 to 1.3	.97	0.9	0.7 to 1.3	.59
Conducted by federal government	0.4	0.3 to 0.5	<.001	0.3	0.2 to 0.6	<.001
Conducted by health care provider	1.9	1.4 to 2.4	<.001	1.3	1.0 to 1.8	.08
Community involved in developing study	0.8	0.6 to 1.0	.09	0.9	0.6 to 1.3	.56
Community involved in collecting data	0.8	0.6 to 1.0	.06	0.7	0.5 to 1.0	.09
Community involved in interpreting results	0.7	0.5 to 0.9	.009	0.8	0.5 to 1.1	.18
Risk that confidentiality might be broken	0.1	0.0 to 0.2	<.001	0.2	0.1 to 0.3	<.001
Participants will not be paid	0.5	0.3 to 0.6	<.001	0.5	0.4 to 0.8	.004
Study is about diabetes	1.5	1.1 to 2.0	.008	2.3	1.6 to 3.5	<.001
Study is about alcoholism	1.2	0.9 to 1.6	.32	1.3	0.8 to 1.9	.28
Vignette 3. Clinical Drug Trial		*n* =3,136*			*n* =1,034*	
Conducted by state university	1.1	0.9 to 1.3	.58	1.1	0.8 to 1.6	.48
Conducted by federal government	0.6	0.5 to 0.8	<.001	0.4	0.2 to 0.7	.002
Conducted by health care provider	1.5	1.3 to 1.9	<.001	1.4	0.9 to 1.9	.10
Community involved in developing study	1.0	0.8 to 1.2	.81	0.9	0.6 to 1.4	.74
Community involved in collecting data	1.1	0.9 to 1.3	.50	0.9	0.6 to 1.4	.76
Community involved in interpreting results	1.1	0.9 to 1.4	.43	0.9	0.6 to 1.4	.76
Risk that confidentiality might be broken	0.3	0.2 to 0.4	<.001	0.2	0.1 to 0.5	<.001
Participants will not be paid	0.8	0.6 to 1.0	.02	0.6	0.3 to 1.1	.09
Study is about diabetes	1.9	1.5 to 2.5	<.001	3.4	2.0 to 5.6	<.001
Study is about alcoholism	1.9	1.5 to 2.5	<.001	1.9	1.1 to 3.2	.02

**Because of the special data structure used in the analysis (see section on statistical analyses), n = the number of question responses analyzed in each logistic regression, not the number of respondents.*

CI, confidence interval; OR, odds ratio.

the hypothetical studies significantly influenced the likelihood of participation among our respondents. Surprisingly, except for the behavioral vignette, engaging the community in developing the study, collecting the data, or interpreting the results did not increase the odds of participation, which may indicate that community members recognize the need for outside technical expertise. Like findings from the literature on survey response rates, we found that participation rates were strongly and negatively affected by concerns regarding breaking of confidentiality and lack of payment, and positively affected by the topic being studied.[34–37]

Our study has several limitations. Although vignette-based research is an established form of qualitative research,[38,39] it has not been widely used in quantitative research. Our use of vignettes may not have adequately captured all relevant constructs, especially because our survey was brief enough to be completed in a waiting room. In addition, because the patients and staff of an urban Indian health care facility are not representative of all AI/ANs, our findings cannot be generalized to other settings, rural AI/AN populations, or individual tribes. Finally, these hypothetical scenarios may not accurately reflect decisions that individuals make when presented with opportunities to participate in actual studies. In this regard, our actual response rates for this study were far higher than those for any of the hypothetical vignettes, suggesting AI/ANs are quite willing to engage in minimally demanding forms of research.

In conclusion, despite numerous and important objections to research in AI/AN communities, individuals appear willing to participate in diverse studies, especially if they are conducted by trusted entities, meaningfully involve the community in appropriate ways, maintain confidentiality, compensate participants, and address salient community health concerns. As among the general population,[34,36] close attention to institutional sponsorship, community involvement, human subjects' issues, and topic of inquiry are essential elements in conceptualizing, designing, and implementing successful investigations on health among AI/ANs.

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