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Critical Contexts for Biomedical Research in a Native American Community: Health Care, History, and Community Survival

Puneet Chawla Sahota

INTRODUCTION

Biomedical research is an integral part of biomedicine and is a rich topic for ethnographic study. Despite National Institutes of Health (NIH) guidelines calling for increased inclusion of ethnic minority groups in biomedical studies, there is a dearth of published literature on these groups' experiences with biomedical research. Native Americans in particular are underrepresented in past literature on research participants' perspectives.¹ Ethnographic and qualitative interview studies might shed light on broader historical, political-economic, and social factors impacting ethnic minority groups' decision-making processes about biomedical research participation. This paper reports the results from a qualitative interview study on Native American community members' perspectives on biomedical research. In-depth interviews were conducted with fifty-three members of one Native American tribe located in the Southwest near an urban area.²

Key findings of this study are:

- (1) Many interviewees viewed research as a needed source of health care, perhaps due to historically limited health care resources in the community; and

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(2) Historical federal policies, such as efforts to “assimilate” Native American communities and the forced sterilization of Native women, affected interviewees’ views on biomedical research in complex ways. Research was viewed with mistrust, but also as a tool that can help the tribe address type 2 diabetes and have a strong future.

BACKGROUND

There is a dearth of studies about biomedical research participants’ perspectives and reasons for enrolling in research, although one such large survey study is ongoing.³ The few studies that have been published reported that individuals participate in biomedical research for both personal gain and altruistic reasons.⁴ There are even fewer studies examining differences in research participant perspectives based on ethnic group or socioeconomic status. In two recent studies, limited access to health care likely impacted research participants’ decisions to enroll. Lamvu et al. interviewed 1,106 women who participated in a prospective cohort study of pregnancy that included Caucasians, African Americans, Hispanics, and members of other ethnic groups.⁵ They found that African American women were significantly less likely than white women to name advancing scientific knowledge as their reason for research participation, and were more likely to cite health monitoring and a desire to learn about their pregnancies. The authors hypothesized that these findings might be explained by differential access to health care for African American and Caucasian women. Gorelick et al. also found that lack of access to regular health care was an important reason individuals chose to participate in research studies.⁶

Studies of international clinical trials have also shown that gaining access to health care is a major reason individuals choose to participate. Fairhead, Leach, and Small conducted an ethnographic study of a childhood pneumococcal vaccine trial in The Gambia.⁷ They concluded that individuals with no other source of health care may feel pressured to enroll in research studies to obtain health care services. Madsen et al. studied non-cancer clinical trial participants’ attitudes towards research in Denmark, finding that a major reason individuals participated in research was because they hoped the study would treat them as “special, handpicked patients.” The authors concluded that the regular care available to patients was not “satisfactory” and argued their results show an overall “need for creating equity in patient care” rather than specific changes in biomedical research procedures.⁸ Similarly, Petryna critically examined drug trials within the broader context of health care access, and showed that pharmaceutical companies choose to conduct drug trials in developing nations because it is easier to recruit research participants in contexts with poor health

care.⁹ Further ethnographic and qualitative interview studies of biomedical research are important for understanding the broader social and political-economic inequities that may make certain groups more likely to participate in biomedical research or be recruited for such studies.

Rather than describing individuals' motivations for research participation, most previous studies of biomedical research participants focused on their comprehension of research protocols (such as study purpose, medication side effects, and definitions of placebo and randomization). Such studies conducted in the United States have shown that large proportions of research participants (the majority in some reports) often do not recall basic aspects of research protocols even after completing the informed consent process.¹⁰ A study of participants in influenza vaccine trials in South Africa reported similar results.¹¹ Factors often correlated with poor comprehension of informed consent forms are lower levels of education and older age, as well as less careful reading of informed consent forms.¹² Griffin et al. found that "black and other non-white race or ethnic groups were more than two and a half times as likely to incorrectly identify the study's purpose."¹³ The authors also noted that few studies have examined racial differences in research participants' experiences with the informed consent process. Thus, past studies have demonstrated differences in how members of diverse racial groups and socioeconomic status understand the informed consent process. However, there is limited literature on individuals' actual experiences of participating in biomedical research. By examining a Native American community's relationship with biomedical research, the results presented here demonstrate that qualitative approaches can help to elucidate the complex factors determining how members of diverse groups interact with biomedical research. This study also attempts to fill gaps in past literature by examining the experiences of Native Americans, who are underrepresented in previous reports.

US ethnic minority groups have significant health disparities compared with Caucasians, particularly for chronic diseases such as cancer, heart disease, and diabetes.¹⁴ Native Americans have a high prevalence of diabetes (15 percent), nearly all of which is type 2 diabetes, and this prevalence is more than twice that of the general US population.¹⁵ Despite the serious health disparities between Native Americans and the rest of the US population, health care services for Native Americans have been sorely underfunded. Until very recent budget increases for the Indian Health Service (IHS), the per capita amount allotted for Native Americans served by IHS was \$1,600 per year, which is less than that for health care for federal prisoners and about 50 percent below per-person expenditures by public and private health insurance plans.¹⁶ This situation has improved somewhat in recent years because of increased funding for diabetes prevention efforts in Native American communities. The Special

Diabetes Program for Indians, which the IHS administers, was authorized by Congress in 1997 and provides support for Native American communities to develop their own diabetes treatment or prevention efforts. This program has resulted in modest improvements in blood glucose control for participating communities.¹⁷ However, per capita health care expenditures for Native Americans remain substantially lower than those for other Americans.¹⁸

The study reported here draws on principles of Tribal Participatory Research (TPR), which includes tribal oversight of a research project (that is, a tribal council resolution authorizing the project to be conducted).¹⁹ In TPR, researchers treat the tribe as a partner throughout all stages of a study. This study was developed in partnership with the Tribal Department of Health and Human Services and was then approved by the tribal council. The study was also approved by the Institutional Review Board at the author's university. Additionally, this study used principles of "responsive interviewing" as developed by Rubin and Rubin.²⁰ As these authors recommend, interviewees were treated as "conversational partners" deserving of respect and provided with the opportunity to review and edit their own interview transcripts.²¹ The overall guiding principle of this study was that both the tribe and individual interviewees were partners in the work who had input on the study process, including how they were portrayed. For example, the tribe's desire not to be identified in research publications was honored, and individual interviewees had editorial control over their quotations in transcripts.

METHODS

In-depth, semi-structured interviews were conducted with fifty-three tribal members concerning their experiences with biomedical research. All interviews were conducted by the author. Community members were recruited and identified for interviews in diverse community settings over eighteen months (2006–2007). These included health care settings (such as clinics, health fairs, and disease-based support groups), tribal language classes, and daily community life. Interviewees were purposively recruited in order to include an approximately equal number of individuals with and without type 2 diabetes, as well as those who had and had not participated in past research studies (see table below under "Results" for the sampling frame and final numbers of interviewees in each group). This sampling frame was used in order to independently assess whether (1) diabetes status and (2) past participation in research studies were each linked to specific perspectives on biomedical research among the interviewees. Type 2 diabetes is prevalent in the community, and past biomedical research studies conducted among tribal members have all been

related to diabetes. For this reason, diabetes diagnosis was a variable of interest in examining community members' views on biomedical research.

Interview questions were developed in partnership with the Tribal Department of Health and Human Services. The interview questionnaire included sections about: (1) past experiences with and opinions about biomedical research; (2) perceptions of diabetes and diabetes risk; and (3) perspectives on the handling of biological specimens and related genetic data in research studies. This paper reports specifically on interviewees' responses to the first section of questions regarding their experiences and opinions related to past biomedical research studies. Results from the other interview sections are reported in separate papers. Interview questions asked for this paper were:

- (1) Have you ever been part of a research study in the community?
- (2) Have you heard about any research projects happening in the community?

If interviewees reported participating in or hearing about a research project, they were then asked,

- (3) What do you think the study was about?
- (4) Who do you think was doing the research?

Past research participants were asked,

- (5) Why did you agree to be part of the research?
- (6) Did you get something positive out of participating in the research?
- (7) Do you feel there were any negative aspects or downsides for you in participating in the research?

All interviewees were finally asked,

- (8) Have you learned anything new about health issues because of research here in the community?
- (9) Have you made any changes in your behavior (for example, health habits) because of research here in the community?
- (10) Have you heard about cases where the community or other tribes have had problems with research? If so, please tell me about it.

All interviewees gave informed consent. Interviews were tape-recorded with permission and then transcribed. Interview transcripts were coded line-by-line using NVivo software.²² Data were coded in detail using themes that emerged directly from the transcripts; no codes were defined prior to beginning data analysis, except for categorical demographic variables (such as diabetes status, past research participation, and gender). Following a comprehensive review of all codes, interviewees' answers were tallied by demographic variables of interest (for example, past research participation, diabetes status, gender, and education level).

RESULTS

Interviewee Characteristics

Approximately half of the interviewees had participated in past biomedical research studies (N = 27) while the remaining interviewees had not (N = 26). Similarly, approximately half of the interviewees had been diagnosed with diabetes (N = 27) while the others had not (N = 26).

TABLE
INTERVIEW SAMPLE BY PAST RESEARCH PARTICIPATION,
DIABETES, AND GENDER

Diabetes	Past Research Participation			
	No		Yes	
No	Men	Women	Men	Women
	6	7	6	7
Yes	Men	Women	Men	Women
	6	7	6	8

Table note: Numbers of interviewees are shown by past research participation, diabetes status, and gender.

While the interview sample was not randomly selected, the interviewees were diverse in their age (range: 18 to 73 years), religious affiliation, tribal affiliation (many interviewees identified with multiple tribes), employment status/field, and education levels. Community members who had and had not participated in research had similar levels of education, although those who had participated in past research studies were somewhat older than those who had not (research participants: range = 18–73 years, mean = 51 years; non-participants: range = 18–66 years, mean = 43 years).

Because this study was mainly qualitative, the quantitative data presented below should be interpreted cautiously. The proportion of interviewees who expressed particular perspectives does not necessarily reflect the prevalence of those views in the community overall. The coding process yielded two major themes that are discussed in detail below. First, research was viewed as a source of health care. Second, historical federal policies related to Native Americans, such as “assimilation” policies, have shaped how interviewees currently relate to research in complex ways.

Research as a Source of Health Care

Research studies in the community were an important source of preventive health care for some interviewees (N = 11, 41 percent of past research participants) and as such, these studies filled a unique niche in the spectrum of health care resources sought by community members. Of the eleven interviewees who

saw research as a needed source of health care, four had diabetes and seven did not. These interviewees explained that the main reason they joined research studies was because they wanted to prevent disease, particularly diabetes and its complications. They felt that research studies provided help with managing diet and exercise habits through intensive educational programs and tools like pedometers.

Other community members (N = 8; 30 percent of past research participants) said they joined research studies because they wanted regular health monitoring or diagnostic laboratory tests that were not available as part of their regular health care. Of this subgroup of interviewees, six had diabetes. Among all interviewees who viewed research as an important source of preventive health care or health monitoring, an important theme was that the services they received in research studies were not available through their regular health care providers. For example, one community member said:

Because of the study, I probably got a test that I wouldn't have never gotten. . . . Maybe if the doctor heard something, like in my heart, then I think eventually, I may have had that [test]. Or if I, myself, had maybe an insurance primary doctor that was doing my annual [exam] and [I] said, can you run some tests on my heart? 'Cause with IHS, they don't do a lot of preventive tests like that, it's only after they find something. So I think that was the reason why I did it [joined the study], to get that.

Thus, research studies gave community members access to certain services (for example, preventive laboratory testing, health education) that were not available through their regular health care providers.

Interestingly, interviewees who viewed research as a significant source of health care were generally older and more highly educated than the general interview sample. Of the eleven past research participants who viewed research as a source of preventive care, five had completed undergraduate or graduate degrees and eight were over the age of forty-five. Similarly, of the eight interviewees who joined research studies in order to receive regular health monitoring or laboratory testing, five had completed undergraduate or graduate degrees and six were more than forty-five years old.

For a subgroup of interviewees (N = 3, 11 percent of all research participants) research studies were perceived *primarily* as health care programs whose central purpose was providing health services to tribal members. In other words, these interviewees did not think they were participating in research studies at all, but rather thought they had enrolled in a health care program. These three interviewees denied participating in research at first. However, they answered “yes” when asked if they had been part of the three specific biomedical studies recently conducted on the reservation, which were mentioned by

name. Thereafter in the interviews, they referred to themselves as “patients” and the research study as a “program.” When specifically asked for clarification about whether the study was “research” or “health care,” these interviewees endorsed the latter option.

The perception that research studies are a type of health care “program” was also reflected by which entity interviewees thought was conducting research studies. Interviewees perceived the Indian Health Service (IHS) as conducting the study more often than any other institution. Of twenty-nine interviewees who identified any perceived institution, thirteen (44 percent) named the IHS. The majority of the thirteen individuals naming the IHS had diabetes (N = 9). Some of the interviewees who thought IHS was conducting research (N = 4) explained that they had this perception because their study appointments were at IHS facilities or because IHS health care staff performed clinical procedures in studies. While the IHS was involved as a collaborator for some of the studies, it was not the principal investigator for any of them, and its main purpose is to provide health care to Native Americans. For some research participants, the perception that IHS was conducting studies made them more willing to participate. For example, one interviewee said, “Part of the reason we were in the study is I knew that it was sanctioned by the Indian Health Service.”

It is likely that the perspectives of community members who were also study recruiters was another factor contributing to interviewees’ perceptions of research as a source of health care. During their interviews, two community members revealed that they had served as recruiters for separate biomedical research studies that had been conducted in the community. While speaking to the interviewer, they reflected on their experiences serving as recruiters and the resulting impacts on their perceptions of research. Both of them saw research projects primarily as a source of health care. The first recruiter said that she figured out only after the research study had ended that it was not meant to be a regular source of health care and that she was disappointed because there was no lasting change in health care provision or health status for the community. In describing her experience with the study, she said, “We recruiters didn’t know much about research design. We saw the study as an extension of regular health care, as an alternative source of health care—a new program.”

Similarly, the second recruiter interviewed said that her main motivation for recruiting community elders for the study was to help them access health care. When asked to describe the purpose of the research study, she said “they were trying to help them . . . to keep their heart pumping. . . . It was a good thing to have a facility come out and help them come out of their homes and do this exam. Because I don’t think they get exams regularly through their [doctor’s] appointments.” Like other interviewees, this recruiter

thought the study provided health care services not otherwise available to community members. However, the research study for which she worked was an observational study of the natural progression of heart disease, and the primary purpose of physical examinations was to collect data, not to provide disease treatment.

One community member interviewee spontaneously shared that she became interested in a biomedical study after hearing a presentation by one of the recruiters (not those quoted above) at a community meeting. She said:

I remember one testimony that [the recruiter for the study] did. Somebody suggested that she [the recruiter] go visit the study, and when she went, they discovered that there was blockage in the arteries, and had she not obtained the treatment . . . she may not have had the long life that she has now. She encouraged community members, if they ever had an opportunity, to become part of that study because all it does is it provides information for you and your family. That kind of always stuck out in my mind as her testimony.

It was not possible to directly observe interactions between recruiters and potential research participants, or between study investigators and their recruiter employees, because all of the biomedical studies were conducted several years before the interviews reported here. As a result, the role of recruiters' training in shaping their perceptions of research vis-à-vis health care programs could not be directly evaluated. Nonetheless, the interview excerpts above suggest that recruiters play an important role in how community members come to view research studies as a source of health care.

Federal Policies and Interviewees' Perceptions of Biomedical Research

The history of federal policies related to Native Americans impacted community members' current perceptions of biomedical research. For example, concerns about the IHS conducting forced sterilizations of Native American women were spontaneously expressed by a few interviewees (N = 4) when they were asked if they had heard of any problems regarding research in Native American communities (question 10 above). Although they were specifically asked a question about research, these community members answered by discussing perceived historical problems with health care. For example, one interviewee shared his fears about IHS possibly conducting research studies and forced sterilizations without obtaining informed consent. He said:

At one time, there was something done with the Indian hospital programs, and they gave out these little white pills for colds, and they contained ephedrine or something or another that sped up your metabolism, and I never saw them any place else. . . . Then, they started selling them years later over-the-counter. I'm

wondering: was this something we did as a study without knowing it? There's a lot of things going on at the Indian hospital that people don't understand, and you know, are we just guinea pigs again? . . . In the '60s, '50s, and '40s, there was even cases where people were saying they were fixing women to where they couldn't have kids. . . . Anything medical, people take with a grain of salt.

The key issue for interviewees who raised the topic of forced sterilizations was the lack of informed consent, which was a larger concern they had about past practices in both research and health care.

Some community members (N = 5) expressed anxiety that they or their family members might have been included in research by the IHS without their consent. None of these community members had participated in research and said they were unlikely to do so because they did not trust researchers to be ethical. They spontaneously raised these concerns and were not specifically asked about them by the interviewer. In some cases, these interviewees explained they were afraid they might have been included in research by the IHS against their will in response to the question, "Have you been part of a research study?" (question 1 above). For example, one tribal member said, "Not that I'm aware of. But, well, there's things that are said—like, for example, when I was eight years old, my grandfather passed away, and that was at IHS. They talked about utilizing body parts for research and stuff, and I remember the adults talking about that. It almost wasn't a choice. I don't even know if that was real or not, but . . . I just remember that being talked about, even as a child. You go to the Indian hospital, and you'll end up as a research." Like this community member, other interviewees who were suspicious of the IHS were also distrustful of researchers. They were often afraid that researchers might violate the confidentiality of research participants or that they would use biological specimens in experiments without research participants' consent.

Beyond health care, historical federal policies aimed at "assimilating" Native Americans and destroying Native American languages and cultures are also part of the political-economic context that shapes how community members view research and diabetes. Several interviewees (N = 13) explained that access to research studies was critical for their community—"desperately needed," as one interviewee said—because these studies would provide a "cure" for the diabetes epidemic. The majority of these thirteen interviewees (N = 9) did not have diabetes. For some of these interviewees (N = 6, three with diabetes and three without), the quest for this cure is urgent because of their fear that the community's very existence, both physical and cultural, is threatened by diabetes. These interviewees used phrases like "extinction" and "the community might not exist anymore" to explain their fears about what diabetes might ultimately mean for their community's collective well-being.

In their comments, they linked the diabetes epidemic to historical traumas faced by Native American communities. For example, one interviewee said:

These white people are killing us. . . . They took our land, what else is there to take, other than our lives too? A long time ago, they've always tried to—what would you say? Not reorganize, but redo us. You know, take our language, take our culture, put a lot of tribes and this community in boarding homes, take us off the reservation. They tried to make us white. I mean, look at what they bring across. They bring plates across, they bring their foods across too. Foods that we weren't even accustomed to, which were bad for us and still are.

These interviewees' comments often referred to federal government policies aimed at "assimilating" Native Americans, such as the forced removal of children from their homes to attend off-reservation boarding schools, where they were not allowed to speak Native languages. Yet this subgroup of interviewees also saw biomedical research as a way to address their concerns about the "extinction" of their community. For example, one of these interviewees said of the high prevalence of diabetes in the community, "It's something that could eradicate the society, it could make the society become extinct . . . We could all perish because of it . . . the percentages of the gene carrying on and mutating from generation to generation is overwhelming. I think that's an area of study that probably needs to be addressed."

Thus, historical federal policies related to Native Americans, such as forced sterilization, caused some community members to mistrust biomedical research. However, interviewees also saw research as a tool to help the tribe overcome challenges like the current diabetes epidemic. Research is one strategy being used by the tribal government to address diabetes. The tribal council recently partnered with a research group to conduct new studies on the genetics of diabetes in the community. For this partnership, the tribal government attempted to protect its collective interests and minimize risks to its members through developing carefully crafted templates for a research contract, scientific protocol, and informed consent form. Over the years, independent of IHS, the tribe has invested significant resources into developing its own comprehensive diabetes prevention program, which includes fitness centers and diet education. Thus, the tribe is working on multiple fronts to deal with diabetes, with engagement in biomedical research as one priority area.

DISCUSSION AND CONCLUSIONS

Community members' perspectives on biomedical research have been shaped by historical factors, including a lack of adequate health care resources and federal policies of assimilation and forced sterilization. Tribal members' views

on research are complex. There was some mistrust of both health care and research. Yet biomedical research studies were often viewed as a necessary source of health care and a tool to help the tribe overcome the threat of “extinction” posed by the diabetes epidemic.

The boundary between research and health care was blurry for many interviewees. It is likely that recruiters’ portrayals of research studies impacted community members’ view that research was a source of health care. Community members hired as study recruiters took on new roles within their community, acting as liaisons and “salespeople” for the research study. The close collaborative relationships between researchers and the IHS (which were formed to improve both research and health care practices) also contributed to the intertwining of research and health care for community members, some of whom perceived the IHS as the primary research institution even when this was not the case. Sankar’s ethnographic study of American cancer drug trials showed that the way a researcher frames a particular project can cause research participants to think they have enrolled in a health care program instead of a research study. This perception is known in bioethics literature as the “therapeutic misconception.”²³ In other studies of research participants’ perceptions, a minority held the therapeutic misconception (less than 10 percent).²⁴ Similarly, in the study reported here a relatively small proportion of past research participants (11 percent) believed they had enrolled in a health care program (three out of twenty-seven research participants).

While a minority of research participants held the therapeutic misconception, many community members participating in biomedical studies viewed research as an important source of health care. Tribal members who held this view were also more likely to have diabetes, which may be because individuals with the disease need more regular health care monitoring than those without it. Previous studies of the informed consent process have shown that lower levels of education and older age are correlated with lower comprehension of research study protocols and informed consent forms.²⁵ In the study reported here, however, community members who viewed research as a source of health care had higher levels of education and were generally older than the overall interview sample. Given the relatively small sample size of this study, this data should be interpreted with caution. It is possible that the higher level of education in the past research participants is simply a reflection of that subgroup being older than nonparticipants. Another possible explanation is that tribal members with higher levels of education may have been more likely to seek health care in general. If so, then they may also have been more likely to seek out what they perceived as alternative sources of health care (such as research) than community members with lower levels of education.

Some community members felt there was an urgent need for research on diabetes because the disease threatened the community's survival. Interestingly, a majority of these individuals did not have diabetes themselves. This fear for the community's future was rooted in larger federal policies of assimilation and forced sterilization. Many community members were barely one or two generations removed from the traumatic effects of these policies. From 1940 to the 1960s, Native Americans were frequently relocated from their reservations to urban areas and some tribes were de-recognized by the federal government.²⁶ Until the 1970s, Native American children were commonly taken from their homes and placed in off-reservation boarding schools where they were forbidden to speak their native languages and were sometimes physically or sexually abused.²⁷ Literature on the history of forced sterilizations conducted by the IHS in the 1960s and 1970s reports that there was a lack of informed consent.²⁸ This recent history continues to reverberate throughout Native American communities today, contributing to what Brave Heart and DeBruyn termed "historical unresolved grief."²⁹ One could argue that fears about the community's survival are justified by recent history.

Scholars who have conducted ethnographic studies on the diabetes epidemic in Native American communities connect this disease to a larger history of marginalization and injustice.³⁰ For example, Mariana Ferreira found that California Yurok community members attributed the high incidence of diabetes to historical "violence and brutality of Spanish conquistadors, fur traders, gold miners, American soldiers, and Indian policies of the United States government since the eighteenth century."³¹ Similarly, Gretchen Lang reported that her conversations about diabetes with members of the Devil's Lake Sioux Tribe "invariably turned to changes in the community during the late 19th century and for most of the 20th century, including decades of food scarcity, unemployment, dependence on government rations, and later, commodity foods."³²

The political-economic context for Native American health has improved since the biomedical research studies discussed in this paper began. For example, the Special Diabetes Program for Indians has grown and now includes nearly four hundred community-run programs for diabetes prevention or treatment.³³ Tribes have also formed their own diabetes prevention programs that are independent of the IHS. The community described in this paper has an active and strong tribal diabetes prevention program, with fitness centers, diabetes educators, dietitians, and physical fitness specialists. When the research studies discussed in this paper were first started, the tribal diabetes program was still developing and growing. Today, community members might not consider research to be a necessary source of health care because of the extensive diabetes services provided by the tribe. However,

all Native American communities do not have the resources to develop such extensive diabetes programs. Furthermore, even with funding for the Special Diabetes Program for Indians, per capita expenditures for health care services provided to Native Americans remain substantially lower than those for other Americans. This disparity in funding is a primary cause of the high mortality rates among Native Americans, which have been increasing over the last two decades largely due to complications of type 2 diabetes.³⁴

Interviewees' perspectives on biomedical research studies demonstrate an eagerness for preventive health care services and programs aimed at managing diabetes. Their views substantiate the recent increase in federal funding for diabetes prevention and management efforts in Native American communities and show that further resources for such programs are needed and will be well used. Furthermore, increased health care resources might also improve the relationship between Native American communities and biomedical research. Strong partnerships between tribal communities and researchers would help to ensure that future biomedical research studies will truly benefit Native Americans and will be seen as distinct from health care services in community settings. In particular, for biomedical research to be truly helpful to Native American communities, it is important that tribes be involved in defining processes of recruitment, informed consent, and the very questions that are studied.

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NOTES

1. National Institutes of Health, "NIH Policy and Guidelines on the Inclusion of Women and Minorities as Subjects in Clinical Research," October 2001, http://grants.nih.gov/grants/funding/women_min/guidelines_amended_10_2001.htm.

2. The tribe has adopted a policy of remaining anonymous in all research publications and presentations. As a result, the tribe is not named in this paper, but simply referred to generally as "the community" or "the tribe." Similarly, past biomedical research studies conducted in the community are

also not named, because to do so might compromise the anonymity of the tribe as well as individual community members who were interviewed.

3. Because of the lack of studies on research participants' perspectives, the National Children's Study group recently developed the Research Participant Perception Survey questionnaire for its project. More information about this survey is available here: <http://clinicaltrials.gov/ct2/show/NCT01129869>.

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