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## American Indian/Alaska Native Willingness to Provide Biological Samples for Research Purposes

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## Abstract

This article examines the willingness of American Indian/Alaska Natives (AI/AN) to provide biological samples for research purposes. Prior cases of abuse and misuse of individuals, materials, and data highlight ethical research concerns. Investigators may be hesitant to engage AI/ANs in research projects. We conducted a survey of AI/ANs in the central plains region of the US over 1 year. This convenience sample completed a series of questions on biological samples and research. Survey results (N = 998) indicate that 70.15% of AI/ANs would be willing to provide saliva/spit for a specific study with the proper consent and control of samples. In conclusion, researchers should find ways to work with and for AI/ANs, assuring participant input in the research process.

## Keywords

American Indian/Alaska Native; Biological sample; Ethics; Participation

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## Introduction

Several medical studies have reported findings based on biological samples from the American Indian/Alaska Native (AI/AN) population [1–3]. These studies reference blood and other tissue, saliva, and genetic samples. However, many studies do not explain how the samples were collected (i.e., data extracted from a database, health records, or collected as part of the research itself). Some studies are explicit when it comes to data collection techniques, where others remain obtuse. Studies like the Strong Heart Study [4–6], the Zuni Kidney Project [7–9], and the Cherokee Diabetes Study [10] focus on AI/AN and use biological sampling with full permission from participants to collect samples for research purposes. However, it is common for studies to extract data from medical records or previously collected samples [11].

In addition, it is difficult to assess whether the participants gave full consent for sample use [12, 13]. Are participants providing samples for one outlined project or a variety of future projects [14]? These issues provide a contextual dilemma, because participants and potential participants should be assured of the proper use of samples; and the agreement between researchers and participants should meet the expectations of both parties [15–17]. Beyond cultivating and maintaining relationships between researchers and participants, investigators have little knowledge of how populations perceive participation in studies. Even if participants provide samples for a particular project, they may be unaware of potential future use. Prior cases of abuse and misuse of individuals, materials, and data highlight ethical research concerns. For example in the recent Havasupai case [18–22], participants agreed to participate in a specific research project; however, participant biological samples were used in research not specified in consent forms. The outcome of the case may result in potential participant and investigator avoidance of requests for collection of biological samples that may be important for improving health indicators or treatments. AI/AN communities may have many justifiable reasons for being reluctant to provide biological samples due to mistrust issues of institutions and scientists. Given these factors, and the lack of studies addressing this topic, it is important to understand current AI/AN willingness to provide biological samples for medical research purposes. This study of AI/AN in the central plains

region of the US provides preliminary information on the beliefs and opinions of this group regarding collection and use of biological and genetic information samples for research.

## Methods

Because there is no comprehensive list of AI/AN residents of Kansas or the region, we used multiple methods to recruit participants for this survey, including: pow wows (N = 207), focus groups (N = 211), health fairs (N = 124), career fairs and conferences (N = 275), and other various American Indian cultural events in the region (N = 181). We recruited a total of 998 AI/AN in the region from May 2008 to December 2009, from a population of men and women who self-identified as AI/AN and were at least 18 years of age. The participation rate for this study was approximately 76% across all methods of recruitment. Participants answered a 130 item self-administered survey which took approximately 20 min to complete, and were reimbursed with a \$10 gift card for their time and participation. The survey included questions about general health (9), participant demographics (7), traditional tobacco use (5), commercial tobacco use (33), knowledge and attitudes related to cancer (17), use of the internet (15), sources of health information and health care (24), and other health-related behaviors (15). This study was approved by the Internal Review Board of the University of Kansas Medical Center, Human Subjects Committee.

We asked the following questions to ascertain information related to providing biological samples for research: (1) "If asked to provide saliva/spit for a specific study I would be willing to"; (2) "If I give permission for my saliva/spit to be used in a research study, other approved studies may also use it without further permission from me"; (3) "If asked to provide blood or other tissue for a specific study I would be willing to"; (4) "If I give permission for my blood or tissue to be used in a research study, other approved studies may also use it without further permission from me". Response categories allowed the participant to "strongly agree, somewhat agree, somewhat disagree, and strongly disagree". Another set of questions specifically targeted genetic testing. (5a) "Have you ever had a genetic test?"; (5b) "If no, would you ever have a genetic test?"; and, (5c) "If yes, how useful was the genetic test information to you or your physician?" There were five possible responses for question (5b), including: (1) "Yes"; (2) "No, I do not believe genetics affect health"; (3) "No, I do not think anyone has the right to my genetic information"; (4) "No, I do not trust what will be done with the information"; and, (5) "No, I am afraid of what I will find out from this kind of test". Lastly, response categories for question (5c) were "very useful, somewhat useful, and not at all useful."

Chi-square tests of association were used to examine the relationships between responses to biological sample questions and independent variables such as gender (male/ female), childhood environment (reservation, rural, suburban/urban), traditional tobacco use (yes/no), whether a participant had a regular healthcare provider (yes/no), and whether a participant had seen both a traditional healer and a Western healthcare provider in the last 12 months (yes to both, traditional healer only, Western provider only). Statistically significant associations and effects were identified by *P* values of less than 0.05. All data analyses were conducted using SAS version 9.3.

## Results

Basic characteristics of our study population are provided in Table 1, totals column. The data reveal that a majority of AI/ ANs would be willing to provide saliva for specific research purposes, regardless of gender (males: 64%, females: 76%, *P* = 0.0011), childhood environment (sub(urban): 75%, rural: 75%, reservation: 64%, *P* = 0.0079), whether they practice traditional tobacco use (yes: 71%, no: 68%, *P* = *ns*), whether they have a regular

healthcare provider (yes: 73%, no: 52%,  $P = 0.0303$ ), and whether they use traditional healers (67%), Western providers (75%), or both (67%,  $P = 0.0123$ ) (Table 1). When asked to use the same material for future approved studies, participation willingness decreased 11–25%, depending on the category (Table 1). Significant differences in willingness to provide saliva for future studies were seen for those who had a regular healthcare provider (25% decrease) versus those that did not (11% decrease), as well as for those who saw both a traditional healer and Western provider (19% decrease) versus only a traditional healer (17% decrease) or only a Western provider (22% decrease). No statistically significant differences were noted in willingness to provide saliva for future studies by gender, childhood environment, or traditional tobacco use, though the overall rates were 14–25% lower in these categories, also (data not shown). While these percentages indicate about half of the population would still be willing to participate, there remains a substantial decline in participation rates without further consent (Table 2).

A similar pattern is seen regarding willingness to provide blood or other tissue for research purposes. More than half of the AI/AN in our sample would be willing to provide blood or other tissue for specific studies, regardless of gender (males: 56%, females: 63%,  $P = ns$ ), childhood environment (sub(urban): 64%, rural: 67%, reservation: 53%,  $P = ns$ ), whether they practice traditional tobacco use (yes: 59%, no: 63%,  $P = ns$ ), whether they have a regular healthcare provider (yes: 63%, no: 52%,  $P = 0.0021$ ), and whether they use traditional healers (57%), Western providers (63%), or both (60%,  $P = ns$ ). Willingness to provide blood or other tissue for future studies without additional informed consent declines 9–15%, depending on the category, with significant differences in whether the participant has a regular healthcare provider (yes: 49%, no: 41%,  $P = 0.0199$ ).

## Discussion

This study provides rates of potential participation by AI/AN in research involving collection of biological samples. The questions posed provide contextual possibilities and limitations for planning future research. Our results indicate that the majority of AI/AN surveyed are willing to submit biological samples for research purposes. While a few recent qualitative studies have explored AI/AN beliefs and opinions about biological samples [23, 24], ours is the first large-scale quantitative study to confirm that AI/AN populations are willing to provide samples with proper consent. For example, participants responded negatively when asked if they would be willing to provide biological samples for other approved studies without further permission. This indicates that AI/AN want to know specifically the kind of research for which their samples will be used and they want to be aware of future studies or “reuse” of their samples. Resistance to participation in future studies, regardless of the type of sample provided (saliva vs. blood or other tissue), suggests that people want to be thoroughly informed prior to giving consent for use of their biological materials for research. Participants want to decide what types of research to participate in based on the study design and goals of the intended project [14–17].

This analysis is limited by the lack of information concerning specific tribal affiliations. Due to particular histories, some tribes may be more willing to provide biological samples than others. We did not run these analyses because of our research agreements, i.e., partitioning the data by tribe may be too identifying. However, our study is strengthened by the examination of a heterogeneous AI/AN population, allowing exploration of a sensitive and timely research issue from a broad native perspective.

Based on these results, investigators should not be timid or apprehensive about partnering with AI/AN populations for medical research. Conducting transparent research may act as a bridge for the perceived strain between researchers and potential AI/AN participants. Sound

and ethical research and direct involvement of participant communities in guiding study plans should be the forces that drive health improvement studies and treatments among underserved populations. These actions will help clarify research intent and avoid potential misunderstandings that the Havasupai participants experienced.

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**Table 1**

Participant views on providing saliva samples for research

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	Totals N (%)
<i>Saliva specific study</i>					
Male N (%)	137 (33.3)	127 (30.9)	62 (15.1)	85 (20.7)	411 (42.5)
Female N (%)	213 (38.3)	207 (37.2)	67 (12.1)	69 (12.4)	556 (57.5)
Total N (%)	350 (36.2)	334 (34.5)	129 (13.3)	154 (16.2)	967
					<i>P</i> < 0.00011
Sub(Urban) N (%)	125 (41.0)	105 (34.4)	31 (10.2)	44 (14.4)	305 (33.4)
Rural N (%)	66 (35.5)	74 (39.8)	21 (11.3)	25 (13.4)	186 (20.4)
Reservation N (%)	134 (31.8)	135 (32.1)	74 (17.6)	78 (18.5)	421 (46.2)
Total N (%)	325 (35.6)	314 (34.4)	126 (13.8)	147 (16.2)	912
					<i>P</i> < 0.0079
See same healthcare provider N (%)	270 (38.5)	242 (34.5)	85 (12.1)	104 (14.9)	701 (73.3)
Do not see same healthcare provider N (%)	76 (29.8)	88 (34.5)	43 (16.9)	48 (18.8)	255 (25.7)
Total N (%)	346 (36.2)	330 (34.5)	128 (13.4)	152 (15.9)	956
					<i>P</i> = 0.0303
Seen both traditional healer and Western provider in last 12 months N (%)	65 (35.9)	56 (30.9)	31 (17.2)	29 (16.0)	181 (21.7)
No, seen only traditional healer N (%)	71 (28.9)	94 (38.2)	40 (16.3)	41 (16.7)	246 (29.4)
No, seen only Western provider N (%)	166 (40.6)	142 (34.7)	38 (34.9)	63 (15.4)	409 (48.9)
Total N (%)	302 (36.1)	292 (34.9)	109 (13.0)	133 (16.0)	836
					<i>P</i> = 0.0123
<i>Saliva future studies</i>					
See same healthcare provider N (%)	175 (24.9)	196 (27.9)	122 (17.4)	209 (29.8)	702 (73.4)
Do not see same healthcare provider N (%)	44 (17.3)	61 (23.9)	72 (28.2)	78 (30.6)	255 (26.7)
Total N (%)	219 (22.9)	257 (26.9)	194 (20.2)	287 (30.0)	957
					<i>P</i> = 0.0008
Seen both traditional healer and Western provider in last 12 months N (%)	45 (24.7)	43 (23.6)	45 (24.7)	49 (26.9)	182 (21.7)
No, seen only traditional healer N (%)	48 (19.4)	75 (30.2)	62 (25.0)	63 (25.4)	248 (29.6)
No, seen only Western provider N (%)	106 (26.0)	108 (26.5)	66 (16.2)	128 (31.3)	408 (48.7)
Total N (%)	199 (23.8)	226 (27.0)	173 (20.6)	240 (28.6)	838
					<i>P</i> = 0.0239

\* Numbers may not total 998 due to missing responses

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**Table 2**

Participant views on providing blood or other tissue samples for research

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	Totals
<i>Blood/tissue specific study</i>					
See same healthcare provider N (%)	190 (27.0)	253 (36.0)	115 (16.3)	146 (20.7)	704 (73.3)
Do not see same healthcare provider N (%)	41 (16.0)	93 (36.3)	54 (21.1)	68 (26.6)	256 (26.7)
Total N (%)					960
					<i>P</i> = 0.0021
<i>Blood/tissue future studies</i>					
See same healthcare provider N (%)	147 (21.1)	196 (28.1)	112 (16.1)	242 (34.7)	697 (73.3)
Do not see same healthcare provider N (%)	35 (13.8)	68 (26.8)	57 (22.4)	94 (37.0)	254 (26.7)
Total N (%)					951
					<i>P</i> = 0.0199