

Understanding Biomonitoring in Native American Communities

Pamela O'Leary

Abstract Biomonitoring is a process used to determine whether or not humans have experienced negative health consequences from interactions with their environment. It can be used as a strong source of evidence in environmental justice situations and can be very useful in Native American communities. However, Native Americans may have cultural concerns with the scientific processes involving the sampling of their body tissues. Due to lack of resources, a tribe may need to work together with a nonprofit to undergo biomonitoring. When these stakeholder groups team up, problems can arise due to cultural misunderstandings. To determine under which circumstances biomonitoring meets the needs of Native Americans, Native Americans and nonprofit members were interviewed about their attitudes on biomonitoring. The interviewees were questioned about their original goals, unexpected challenges, outcomes, and suggestions for improvement. Two case studies were analyzed: 1) the Yu'pik tribe in St. Lawrence Island, Alaska, who underwent biomonitoring in 2001 and 2003; and 2) the Elem Pomo tribe of Clear Lake, California, who are considering undergoing biomonitoring in 2005. The study shows that the long term relationship between the nonprofit and tribe has a significant impact on the biomonitoring process. Tribes need to feel ownership of the data and receive results in a timely manner. A more culturally sensitive situation can be achieved for all stakeholder groups if Native American communities are fully informed and involved in all steps of the process.

Introduction

Biological monitoring, also known as biomonitoring, is a process that uses samples of body fluids and tissues to detect the presence of pollutants in the human body from a person's interaction with their environment (Pirkle 2004). These interactions range from transport exhausts to common consumer products and household appliances (frying pans, children's toys, solvents used in paints, etc.). While blood, urine, breast milk, and expelled air are most commonly measured, hair, nails, fat, and bone may also be sampled. The process of biomonitoring involves: a) selecting who will be monitored and where or when this will happen, b) collecting the samples, and c) deciding which chemicals to test and then analyzing them (Kamrin 2004).

Biomonitoring is the only direct method of determining if people have been exposed to certain substances, what magnitudes they have been exposed to, and how these change over time (Kamrin 2004). In recent years, biomonitoring has become a more useful tool since scientists are now able to detect more minute amounts of chemicals in the human body. The biomonitoring process is used as a tool by environmental campaigners, lobbyists, and governments to assess human exposure to pollution as part of health and environmental policy-making. When high levels of chemical exposure are found, legislators may decide to ban a product or restrict its usage to applications where it presents lower risks for human health (Biomonitoring in health & environment policy-making 2005).

Since some Native American tribes maintain subsistence lifestyles, biomonitoring may be very useful in those communities (Gupta correspondence). However, further research is needed especially in the area of cultural sensitivity. The Washington State Department of Health's Plan for Priorities for Biomonitoring acknowledged that it is unknown what cultural barriers may exist to drawing blood samples from tribes or if tribes are interested in obtaining this type of information data (Washington State Plan for Priorities for Biomonitoring 2003). These unknown issues of cultural sensitivity may lead to significant problems for the tribe. Sherri Norris, a Youth Program Coordinator for the International Indian Treaty Council (IITC) states, "There are so many negative issues about biomonitoring with Native Americans. This is common knowledge amongst native communities. People are not assured that information will not be used for a negative purpose. Most tribes are used as guinea pigs for experiments. The information is not given back to them. They don't know for what purposes it is being used. This goes back to

those eugenics experiments where they weighed people's brains" (personal communication May 4, 2005)

In some instances when biomonitoring has been used in Native American communities, it has not been a positive experience for the Native Americans being tested. The commercial usage of the genetic material of the Pima Indians of Arizona exemplifies this situation. The Pima have the highest rate of diabetes in the world (Ratner 2002). They agreed to participate in a study to determine if the disease had a genetic basis and, supposedly, to develop cures from which the community could benefit. After over 30 years of sample collection and analysis by a broad range of institutions and scientists, no genetic cause for diabetes was found. Instead, the Pima Indian genetic materials and cell-lines have been widely disseminated by genetic data banks and sold as a commodity. In a letter to the United Nations' Commission on Human Rights, the IITC proclaimed, "This commercialization and sale, as a "secondary" use of tissues and cells originally collected for "humanitarian" health purposes, is an example of what indigenous peoples refer to as "biological piracy", the outright theft of resources generated by the commodification of living tissues without permission or compensation" (Indigenous Peoples and Health: Follow Up and Recent Developments 1998). The disastrous experience of the Pima Indians still resides in the memory of Native Americans, especially when they are considering biological testing procedures (Norris correspondence May 1, 2005).

Through presentations and interviews conducted in tribal communities, the IITC has verified that few tribal members, tribal health care providers, or tribal governments are aware of the dangers facing their communities or know how to address them (Complaint v. the United States). When indigenous peoples determine that their health may be at risk, it is difficult for them to discern which state or federal agencies they can turn to for information and effective cleanup. Community leaders who want to sponsor their own sampling or health assessment programs are faced with high costs and lack of resources (Complaint v. the United States). The community of St Lawrence Island Alaska expressed these problems when it declared "...our people have few means for seeking redress and have been left to deal with this toxic legacy on our own" (Gambell Common Council Resolution No. 05-06). When health concerns arise in a native community, they may turn to a nonprofit organization for help.

When a nonprofit organization collaborates with a native community, many challenges exist due to a lack of understanding about tribal culture in non-Indian communities. Cultural barriers exist and are exhibited by a lack of cultural sensitivity and orientation for both cultures resulting in an unwillingness to seek understanding (Final Report 1999). Communication is very much a cultural issue and organizations must be aware of and take into consideration the differences in culture and language among communities and tribes (ASTDR 1999). Tribal leadership and sovereignty are important issues that need to be respected as well. Organizations need to give deference to tribal plans, information, and priorities as well as allow tribes to be involved in planning initial and long term goals (Final Report 1999). Education and capacity building are goals of native communities; tribes need more employment opportunities with other agencies (Final Report 1999). In terms of funding, there is a need for developing programs in a strategic way so when a program reaches completion, the tribe has the knowledge and tools to keep working. When working with a nonprofit, both stakeholder groups must respect and communicate each other's goals and needs to prevent potential problems.

The objective of my study is to determine under what circumstances biomonitoring meets the needs of Native American communities. Through interviews, I will gauge Native American and nonprofit attitudes towards biomonitoring. The case studies of the Yu'pik people of St Lawrence Island, Alaska and the Elem Pomo tribe of Clear Lake, California will be analyzed. Both situations offer insight into the Native American struggle to ensure Superfund status for their lands. I hope to understand the feasibility of biomonitoring as a tool for affected native communities and nonprofit organizations. I will explore the following questions: how do Native Americans respond to the biomonitoring process and what are the goals and outcomes of biomonitoring for Native Americans and involved nonprofit organizations?

Study Sites The Yu'pik tribe is a community of Native Americans that live on St Lawrence Island, Alaska located in the western part of the Bering Sea and very close to Russia. The Air Force acquired the strategically-located Northeast Cape site in 1952 and operated it as a

surveillance station during the cold war from 1952-1972. Beginning in 1982, the Navy used the area as a White Alice communications site and the U.S. Army Corps of Engineers has since assumed responsibility for the cleanup of the formerly used defense site at Northeast Cape (ACAT Fall Newsletter 1998). At request of a tribal elder who thought the tribe's high cancer rates were linked to contamination from the old military site, a nonprofit, Alaska Community Action on Toxics (ACAT) conducted biomonitoring in the form of blood samples in 2001 and 2003. The studies showed that the average PCB level measured in Saint Lawrence Island residents was 7.5 parts per billion (ppb), compared with a national United States average of 0.9-1.5 ppb for people with no unusual PCB exposures (Project Update 2001). The highest levels of PCBs on Saint Lawrence Island were found in people who spent the most time at or near the formerly used military site at Northeast Cape. The Yu'pik people are fighting for this site to be classified as a Superfund site. The most recent progress on this issue was made on April 14, 2004 when a native Yu'pik woman, Viola Waghiyi, a Coordinator for ACAT, testified at the National Environmental Justice Advisory Council (NEJAC) (Project Update 2001). The case study of St Lawrence is an example of a positive experience of biomonitoring for both the nonprofit and tribe.

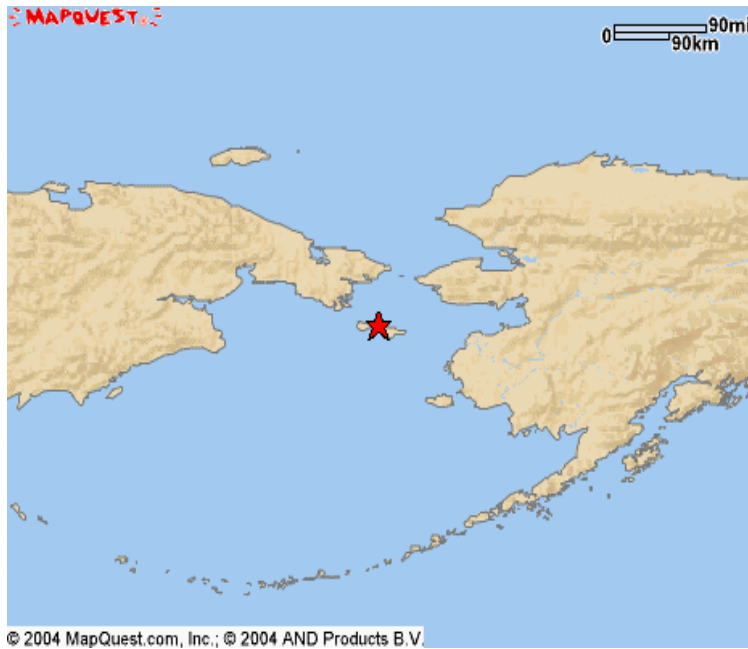
Clear Lake is the largest natural freshwater lake in California and one of the most highly contaminated bodies of water in North America due to mercury contamination (Complaint v. the United States 2005). The levels of mercury in fish from the lake led the state to issue an advisory against eating fish. Clear Lake is also the traditional home of the Elemo Pomo Indians. The Sulphur Bank Mercury Mine is a Superfund site that encompasses the traditional property of the Elem Colony of Pomo Indians and approximately 70 houses are located within 3 miles of the site (Sulphur Bank Mercury Mine 2003). Tribal members have stated that when the Environmental Protection Agency (E.P.A.) finally initiated what they presented as a cleanup program, they merely covered the area in a few feet of dirt and replaced carpeting in some homes (Complaint v. the United States 2005).

Greenpeace has been collaborating with the Environmental Quality Institute at the University of North Carolina (UNC) on a national biomonitoring study of mercury in hair. However, the Natural Resources Defense Council (NRDC) felt that the Greenpeace study had two major limitations: it requires participants to pay \$25 to be included, and it is only sampling people who have access to the Greenpeace website (Correspondence with Solomon December 5, 2004). The

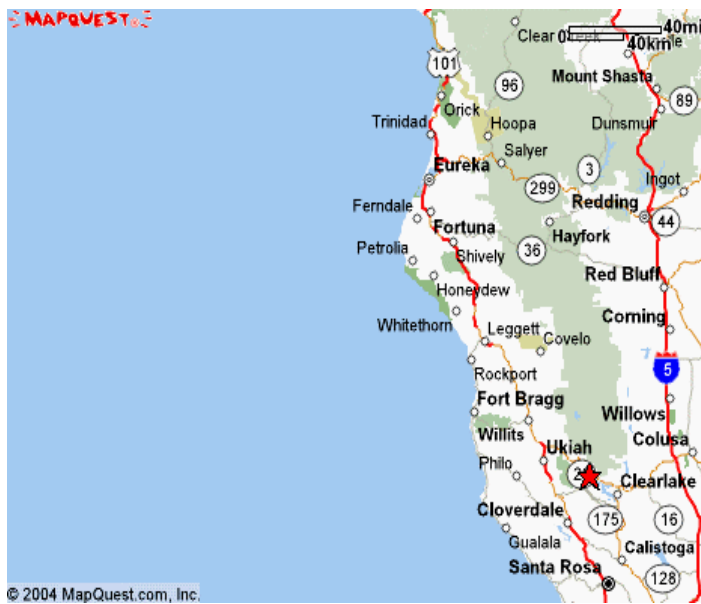
NRDC decided to create a sub-study in the Greenpeace study by subsidizing the costs of the testing therefore allowing anyone to participate regardless of financial status. The NRDC created a collaboration of the following Bay Area nonprofit organizations to implement the hair testing: Clean Water, Center for Environmental Health, International Indian Treaty Council (IITC), and Turtle Island Restoration Network. The International Indian Treaty Council (IITC), who has worked for years with the Elemo Pomo tribe, refused to directly participate with the collaboration. Instead, the IITC invited the NRDC to be one of many speakers at its mercury conference for Northern California tribes in April of 2005. The case study of the Elem Pomo tribe offers an example where biomonitoring is currently under consideration by a Native American community and a nonprofit closely related to the affected tribe is unwilling to spearhead biomonitoring efforts.

Methods

Interviews were conducted with the Yu'pik tribe of St Lawrence, Alaska (Fig. 1) and the Elem Pomo tribe of Clear Lake, California (Fig. 2). Individuals in Alaska were interviewed by phone. In addition to talking to Native Americans who underwent biomonitoring, phone interviews were conducted with Pamela Miller, the Director of ACAT. Due to consent issues, Pamela Miller was only able to give the names and phone numbers of two Native Americans, Jane Kava and Jesse Gologergen, who underwent testing and were employed with ACAT as Community Health Aids. Jane and Jesse gave information for their friends and family who they thought would be willing to be interviewed. Through this way of snowball sampling, a total of five Native Americans were interviewed from St Lawrence Island.



(Fig. 1) Location of St Lawrence Island, Alaska



(Fig. 2) Location of Clear Lake, California

Phone and face to face interviews were conducted for the Clear Lake case. Sherri Norris, a Youth Program Coordinator for the International Indian Treaty Council (IITC) and head

organizer of the IITC's Mercury in Northern California Community Health & Strategy Meeting, was interviewed. Jim Brown, a former Chairman of the Elem Pomo tribe, was interviewed. I attended the Mercury in Northern California Community Health & Strategy Meeting on April 23, 2005.

Semi-structured interviews were conducted with Native Americans and nonprofit officials. The interviewee was informed as to what purposes I was conducting the interview. Interviewees were asked if they want to be anonymous or not and if they did, I assured them confidentiality. A set of guiding questions with follow up questions were used. Notes were taken as the interviews were conducted using direct quotes to keep the data in the words of the interviewee rather than the interviewer. Guiding questions were developed to be simple without using academic jargon or potentially offensive language. A set of general questions was made that focused on the following topics: goals, outcomes, problems, strategies used to counter problems, comfort levels, and constructive criticism. A formal questionnaire was not used for the potential unease it could cause interviewees and because a less formal approach could lead people to more open responses. The following set of guiding questions was used:

For Native Americans

- 1) What did you think of the biomonitoring process? What did other members of the community think of the biomonitoring process?
- 2) Do you think the biomonitoring process had a positive or negative effect on your community?
- 3) Did the biomonitoring process help meet the goals of your community?
- 4) Were there any problems? What did you do about them?
- 5) Would you personally undergo biomonitoring again?

For Nonprofit Officials

- 1) Why did your organization want to use biomonitoring in this community (what was your goal?)
- 2) How did you get the native community involved in biomonitoring?
- 3) During biomonitoring, were there any problems, if so what were they and how did you ameliorate them?
- 4) Did biomonitoring effectively meet your goals for your organization and your goals for the community involved? If not, what could be done better next time?
- 5) How do you think biomonitoring could be done in a more culturally sensitive way?

Results and Discussion

There are a number of limitations to the results of this study. The conclusions drawn, such as those for St Lawrence Island, are not meant to be representative of the entire tribe. They are only the feelings of a few people interviewed. Due to issues of consent, Pamela Miller was only able to disclose the information for Jane Kava and Jesse Gologergen, two Yu'pik natives employed by ACAT. Jesse and Jane gave the names of four other family members and friends. As a result, a significant bias exists because of the close relation of the people interviewed. Additionally, due to the very recent introduction of the biomonitoring program to the Elem Pomo, very few people of the tribe knew of the project's existence and had an opinion on the subject. A bias exists because the sample size consists of only one person who attended the mercury conference of his own volition and already had a predisposition in support of the testing.

Interviews with Native Americans and nonprofit officials from both study sites illustrated similar needs and priorities for both tribes. Consequently, several observations were made about the relationship between a nonprofit organization and native community in the context of biomonitoring. 1) The testing should be conducted by a nonprofit organization rather than by a state or federal agency of the United States government. 2) A previous working relationship between the nonprofit organization and the Native American community facilitates the biomonitoring process. 3) The specialization and degree of initiative of the nonprofit can have a significant affect on the testing process. 4) From the beginning, the community needs to be aware of how their involvement in the testing will directly benefit them. 5) The community wants to feel empowered throughout the testing process and ideally holds leadership roles. 6) Lastly, the community needs to feel ownership of the data and receive results in a timely manner.

Preference of Nonprofit Organizations Both tribes mistrust and dislike the United States government and felt it was the cause of their need for biomonitoring. Therefore, they both preferred to work on a biomonitoring project with a nonprofit organization rather than a state or federal agency. The impetus for Annie Alowa, a Yu'pik elder who was an ACAT Health Aid, to request that ACAT to do testing was because she was concerned the high rate of cancers, as well as birth defects and premature births, were connected to the contamination problems at Northeast Cape. Annie Alowa stated, "I want this to be cleaned up before it is too late. It used to be a good hunting place—now people are scared to pick anything from there. The military treats us as if we were the enemy. I asked them, 'Why do you keep this secret?'" (ACAT Fall Newsletter 1998). Since the Yu'pik felt the United States government was the cause of their problems, they did not

feel they could turn to them for the answers. The Elem shared a similar discontent of collaborating with the government. Jim Brown, a former Chairman of the Elem Pomo tribe, explicitly stated, "We will probably do this because it is not run by the E.P.A" (personal communication April 23, 2005). When the Elem previously underwent mercury hair testing, they were dissatisfied because the E.P.A. did not return their results to them until three years later. Additionally, the Elem have a long history of power struggles with the E.P.A. over the issues of the Sulphur Bank Mercury Mine Superfund site. Cleanup by the EPA has been substandard according to tribal members. The E.P.A originally hired the University of California, Davis Department of Environmental Studies to document the mercury contamination in Clear Lake and the effects on the Elem Pomo tribe. Instead of following the directives found within the report or notifying the community of the dangers they faced, the E.P.A. fired UC Davis from the project (Complaint v. the United States).

Previous Relationship between Tribe and Nonprofit A previous relationship between the tribe and nonprofit smoothes the progress of the biomonitoring process since the tribe is more willing to participate because they trust the organization. Jane Kava, an ACAT Health Aid stated, "The fact that we worked with ACAT before made it easy. ACAT had been around for 5 years and everyone knew about them. We knew anything they do will benefit us" (personal communication March 29, 2005). Jim Brown sympathized with the desire to cooperate with nonprofits, he stated, "We need to ally with environmental groups" (personal communication April 23, 2005). The Elem had a positive experience collaborating with the IITC on its Tribal Health and Mercury Education Project in 2003, so were willing to trust the IITC's suggestion of working with the NRDC on its biomonitoring project (Mercury Contamination and Community Health in Northern California 2003).

Nonprofit Specialization Nonprofit specialization and degree of involvement can affect the biomonitoring process. ACAT is a nonprofit specifically focused on toxics issues in Alaska whereas the IITC is a broad nongovernmental organization that lobbies internationally for indigenous issues. ACAT possessed the resources and knowledge to provide a significant level of involvement in the project. Pamela Miller illustrates the continual desire of ACAT to meet the requests of the tribe, "ACAT was originally interested in solely undertaking environmental sampling, but then the community requested that people be tested so ACAT applied for an environmental justice grant from the National Institute of Environmental Health Sciences. When

the testing was done, the community asked us to make the information public. There were news releases and it was big media up here” (personal communication March 25, 2005).

The IITC was not as willing to spearhead a biomonitoring campaign as ACAT had been. It instead acted merely as a liaison between the tribe and the NRDC, who would direct the biomonitoring efforts. Sherri Norris stated, “Treaty Council has never done biomonitoring before, so we don't want to do something which we have no experience with” (personal communication May 5, 2005). The indirect relationship of the NRDC, who has never worked with the Elem Pomo tribe before, has also slowed down the timeline of the biomonitoring process. Tests were available on March 9, 2005 at the NRDC Mercury Testing Collaboration meeting which was not attended by the IITC. The tribe could already have undergone testing if the IITC played a more direct role in the process.

Community Benefit Awareness The level of awareness of how the community will benefit from biomonitoring affects their willingness to undergo biomonitoring. Jane Kava, an ACAT Health Aid demonstrates this importance, “With this process we could say, ‘Hey we know there's no factories on Savoonga. Why are we getting all this cancer and problems?’ We want to connect the military site with this. We can say yes we're getting it from there and we want to ensure that both places are getting cleaned up as much as we can do. The testing can help us get more funding” (personal communication March 29, 2005). Jesse Gologergen, another ACAT Health Aid reiterates the advantage of community awareness, “It was great and needed to be down out here. Everyone felt that way” (personal communication March 29, 2005).

An additional barrier occurs when the community is not as clear about how the testing will improve their situation, as is the case in Clear Lake. Jim Brown, a former Chairman of the Elem Pomo tribe explained, “We will probably do the mercury testing but we need to convince the tribal council. We need to educate and encourage members that it is important to do. Some people would rather focus on the issue of the casino. Gaming shifts the focus from the environment. I didn't get re-elected because my focus was more tied to the environment” (personal communication April 23, 2005). The Elem have a long history of disappointment from participating in scientific studies which makes a clear explanation of their benefits more important for the testing to occur.

Tribal Empowerment The tribal community wants to be informed and involved in entire process. Jane Kava emphasizes the importance of letting the tribe know exactly what the

biomonitoring procedure entails before it is started; she states, "Pam from ACAT came out with Dr. Sord and Dr. David from New York and told us beforehand exactly what was going to be done. The community was very receptive and willing to help in any way" (personal communication March 29, 2005). But it is also important that communication between the nonprofit and tribe is continued after an initial meeting. Pamela Miller reflecting on the success of the project stated, "We did our study in a culturally sensitive way. The Yu'pik requested it and were involved in the process from the ground up. It was not a group of outside experts. I think that biomonitoring goes wrong when a group of experts come in and say 'you need to have this invasive procedure done.' It's bad when you don't include them in the process except for the Institutional Review Board" (personal communication March 25, 2005).

The role of the Health Aid, a member of the tribe trained and employed by ACAT, offered a unique relationship between the nonprofit and tribe and gave the tribe a positive sense of leadership in the project. Pamela Miller explained, "There were no problems during the biomonitoring because the people drawing the blood were Yu'pik themselves and trained as a Health Aid and became staff of ACAT. Consequently, it was not a "them versus us" situation. Everyone volunteered and was willing to have their blood drawn. The community viewed the blood drawers as a part of their community rather than outsiders interfering in the lives of the local people" (personal communication March 25, 2005).

Sharing of Results Both tribes demonstrated the importance of feeling an ownership of the data and that the results are given back in a timely manner. Pamela Miller felt ACAT met this need and she stated, "Results were provided to the individuals. Individuals who underwent testing were given the opportunity to discuss the results privately with a doctor and discuss the issue through a community setting what it meant to them. The meeting was closed to people from the outside" (personal communication March 25, 2005). Jim Brown emphasized his tribe's fear of reliving their experience with the E.P.A. biomonitoring program in which they did not receive results until years later (personal communication April 23, 2005).

Sherri Norris summarizes the needs of Native Americans by stating, "I would say biomonitoring is best done when it is community driven, there is a secure data base, and the information is protected" (personal communication May 5, 2005). A smooth biomonitoring process for both stakeholder groups can be achieved if the nonprofit involves the community in decision making in all steps of the process: deciding to undergo testing, during testing, and

sharing results with individuals and the public. The nonprofit should informatively communicate with the community during all stages of testing. Directly involving community members in the process, in ways such as employment, makes the community feel more comfortable with the process.

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