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# Informed Consent and the Collection of Biological Samples from Indigenous Populations

## Year

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## Description

This case discusses issues related to obtaining informed consent from those who participate in scientific studies; it asks questions such as: is individual consent sufficient for valid consent if a member is of a larger unit and the use of incentives and is it right to pressure and use deceit to persuade individuals to give their consent.

## Body

Medical geneticist Timothy Tiptree is accompanying anthropologist Karin Kroeber to collect blood samples from the Yuchi, a small indigenous population living in a remote region of New Zealand. Kroeber was the first western scientist to work with and study the Yuchi, after tribal elders initiated contact with local government authorities in the hope of obtaining medical assistance. With the help of a translator, Kroeber coordinated the medical relief effort and then, with the full cooperation and permission of tribal elders, began a long-term ethnographic study of Yuchi culture.

Meanwhile, in the course of screening a random collection of blood samples from a control group of healthy Yuchi donors, Tiptree's laboratory made a startling discovery. Each sample seems to be infected with leukemia-like cells, and yet the

donors are healthy adults. This finding leads Tiptree's research group to speculate that the Yuchi might have developed some natural immunity to leukemia. After a flurry of excited discussions, it is agreed that Tiptree should go to New Zealand to collect additional blood samples from Yuchi families to facilitate locating the gene or genes responsible for the unique characteristics of Yuchi blood.

Kroeber agrees to help Tiptree and obtains tentative permission from the tribe's council of elders to proceed with the additional sampling.

Upon their arrival in New Zealand, however, Tiptree and Kroeber find that the Yuchi are reluctant to go forward with the blood sampling. It turns out that the council thought the additional sampling was part of Kroeber's ongoing project. They are uneasy about working with a different and unknown research team. Also, when pressed, they inform the scientists that it is one thing to take blood for purposes of curing a particular individual and quite another to systematically sample whole families. After much discussion, the council decides to withdraw its permission to take additional samples.

Tiptree is stunned. While his lab was able to identify several DNA markers associated with the Yuchi immunity, they cannot make further progress in locating the gene(s) without additional samples.

What would you do if you were Tiptree?

Tiptree contacts his superiors back home to inform them of the council's decision. His lab director pressures him to try again, this time offering a rather large stipend both to the council and any individual participants. The director makes clear how badly he wants those samples, and how important they are to the lab and the future of cancer research.

At the second meeting, the council of elders declines Tiptree's offer, explaining that they only asked for assistance because their people were sick and that Kroeber's ethnographic study was already a significant disruption. Without the imminent threat of disease, the council simply wants things to get back to normal.

After the meeting, Tiptree confronts Kroeber.

"Karin, can't you talk to these people? Can't you make them see what's at stake here?"

"I don't think we can 'make them' do anything, Tim. Look, this is the first sustained contact the Yuchi have had with western science and I really think we should take it slow, on their terms."

"But all my team needs is to draw some blood! And the Yuchi have already gone through it once before. It's not like it's something new to them. Why can't your group just suspend its work for a few weeks while we get what we need?"

"It's not that simple. We've spent eight months developing a working relationship with the council and the people. And the council is obviously uneasy about more sampling, at least in the short term. Since they constitute the locally recognized governing authority, we have to accept their decision. Why don't you spend some time getting to know them?"

"How much time are we talking here?" "At least a couple of months, Tim. I'm sorry, but trust doesn't come cheaply in these parts of the world."

What would you advise Tiptree to do now?

After thinking it over, Tiptree decides to circumvent the council and approach families directly. This idea was suggested to him by several local government officials who are eager to cooperate with Tiptree's lab.

Without informing the council of elders or Kroeber, Tiptree enlists the help of a translator and contacts a number of families. He employs three strategies to convince them to give blood, in the following order:

1. He explains as clearly as possible that giving blood has the potential to save many lives and that it may lead to new ways to cure disease. He argues that the Yuchi would themselves benefit from such advances.
2. He offers families, especially the poorer ones, various items in exchange for their blood samples (for example, a watch, a radio, binoculars, a stethoscope or the large stipend authorized by his lab director).
3. He tries to convince families that they owe Professor Kroeber and the other relief workers something for the help they have received. He intimates that the Yuchi won't receive any additional help in the future if they choose not to cooperate with Tiptree's team.

Using these strategies, Tiptree successfully collects enough blood samples to enable his lab to locate the gene responsible for the unique characteristics of Yuchi blood. As a result, the lab pioneers a new and promising approach to cancer research.

Are Tiptree's actions justified? Why or why not? What specific additional facts or factors would influence your decision?

## **Discussion Questions**

1. What is "informed consent" in the context of scientific experimentation involving humans?
2. Clearly, the consent of the individuals directly involved in the experiment or procedure must be obtained. However, in a cross-cultural setting, several other parties might play an expanded role: the local governing authority of the population; local, state, or national authorities; and even the group funding the research. Should an investigator have to obtain the permission and cooperation of all these parties in order to conduct research involving human subjects?
3. Assume for the moment that the council did allow Tiptree to proceed with the sampling, on the condition that Tiptree's team get permission from each family head and from each member within that family. Now consider the three strategies Tiptree employs. Are there any problems with the strategies? Does each strategy guarantee "informed consent"? How would you rank the strategies from acceptable to not acceptable? (They might all be acceptable or none of them might be acceptable.)

## **Three Additional Questions to Expand the Case Study**

1. Consider the following alternative endings to the case:

(a) As Tiptree's team is leaving the village, the Council of Elders confronts them and demands that they leave all the samples behind. The council explains that Tiptree must have their permission to take samples and that they consider human blood to be something sacred and only to be "tampered" with if it is a matter of life or death.

Does the council have the right to make this demand? Do they have this right even given the fact that individual families agreed to the sampling and were compensated? (See Strategies 2 and 3.)

(b) As Tiptree's team is leaving the village, Professor Kroeber confronts them and demands that they leave all the samples behind. She explains that Tiptree cannot take the samples without the council's permission and that his actions are jeopardizing her own relationship with the Yuchi as well as her ongoing ethnographic study. What's more, Kroeber tells Tiptree that given the manner in which he obtained the samples, she feels morally obligated to report his actions to the NIH and Tiptree's local IRB.

Is Kroeber's response appropriate?

(c) Imagine that Tiptree offers the following justification for his actions (with respect to scenarios a and b): "I understand why you are upset, but I feel my actions are justified given what's at stake here. I fully acknowledge the authority and rights of the Council of Elders, and I fully acknowledge the value of Professor Kroeber's research project. However, I believe that these samples may well hold the key to a cure for cancer -- and the potential benefits to all of humanity more than justify what I've done."

Is Tiptree's justification convincing? Does it justify his actions?

2. Assume for the sake of argument that the Yuchi blood samples do in fact hold the key to an effective cure for cancer and that without Yuchi blood samples a comparable breakthrough would take significantly longer (say, on the order of at least a decade). Would it be morally justifiable to obtain the samples, even if it meant violating the Yuchi tribe's customs, world view or right to self-determination? Respond to this question using a) a utilitarian framework (where the guiding ethical principle is to maximize happiness and minimize pain for the greatest number) and b) a Kantian framework (where the guiding ethical principle is never to use other humans merely as the means to some end).

3. Informed consent seems to involve another layer of issues in a cross-cultural setting. Special considerations and efforts seem to be called for given the history of exploitation between first and third world cultures, and the often stark contrast between values and ways of life. Do you think that anything we might learn about informed consent in such contexts can be applied to more traditional clinical settings? In particular, does anything we might learn from the cross-cultural context provide a useful perspective on traditional cases of informed consent involving especially vulnerable, oppressed or traditionally under-represented groups (e.g., children, institutionalized patients, women or minorities)? How might our current

concept(s) of informed consent be modified to more humanely engage such groups in the scientific enterprise?

## **Notes**

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