

# **Deborah Johnson's Commentary on "Informed Consent and the Collection of Biological Samples from Indigenous Populations"**

Commentary On

Informed Consent and the Collection of Biological Samples from Indigenous Populations

This case raises two important, interrelated issues. Both have to do with obtaining informed consent from those who participate in scientific studies. The first issue has to do with whether individual consent is sufficient for valid consent when the individuals are members of a larger unit with an authority structure; and the second has to do with the use of incentives, pressure and deceit to persuade individuals to give their consent.

The purpose of the informed consent requirement is to ensure that individuals are not used in research without their knowledge and agreement. The requirement ensures that individuals are respected and their autonomy is recognized. To bypass informed consent is to treat individuals merely as a means to some end, be it knowledge, the researcher's career success, or a social good such as a cure for a disease.

In addition to the informed consent issues, Tiptree is pressuring Kroeber to do things that Kroeber believes may harm the delicate relationship she has developed with a tribe, a relationship Kroeber needs to maintain so that she can continue with her own research. I will not address this aspect of the case except to say that while Tiptree's strategy is not blatantly immoral (Kroeber is free to refuse to help) it is one that probably will not serve him well in the long run. Why should Kroeber help Tiptree in the future when he shows such disregard for Kroeber's own research?

The first apparent breach of research ethics arises when Tiptree circumvents the council and approaches the families directly. Interestingly, from the perspective of

traditional ethical theory, it is not at all clear that this behavior violates any moral principle since traditional ethical theory does not come to grips with an authority such as a tribal council. As long as Tiptree obtains the informed consent of the individuals from whom he obtains blood, I don't believe he is doing anything immoral. In going directly to individuals, however, he is disrespecting the authority of the tribal council. His actions will damage both his future relationship with the tribe and Kroeber's relationship with the tribe. The wrong to Kroeber is the worst of these two, since Kroeber has cooperated with him. Tiptree's behavior will severely damage his relationship with Kroeber.

Of the three strategies that Tiptree proposes to use in obtaining consent from individual members of the tribe, only the first seems to be without problems. With this strategy, Tiptree will inform the individuals about the possible positive results of his research. He also has an obligation to inform them about any potential risks or negative consequences.

The second strategy -- offering the poorer members of the tribe "things" in exchange for the blood samples -- moves informed consent closer to exploitation. When consent is coerced, it is not freely given and, therefore, is not valid. Offering things in exchange for participation is not exactly coercion, but it moves the situation in that direction. Tiptree is taking advantage of the poverty of these members of the tribe. Would they consent if they weren't poor? I hesitate to say that the offer of "things" invalidates the consent because offering compensation is a common practice in medical experimentation. Still, compensation should be flagged as something it would be preferable not to use.

The third strategy crosses the line. It is an immoral strategy because it is manipulative and deceitful. If Tiptree obtains consent by telling members of the tribe that they owe it to Kroeber and suggesting to them that they won't receive help in the future if they don't cooperate with him, he is entirely misrepresenting the the situation This strategy invalidates any consent he may obtain.

Are Tiptree's actions justified, especially given that his research is ultimately successful in locating a leukemia resistant gene? This question is simply a version of: Do the ends justify the means? There may be rare cases in which ends do justify means, but Tiptree is being arrogant and self-serving in presuming that he can do the calculation himself. His attitude is arrogant because it assumes that Tiptree knows better than the Yuchi what their best interests are. Whatever the calculation

of means and ends, Tiptree should not make it since he stands to gain by the outcome.

This case is particularly interesting because of the question it raises about whether it is acceptable for a researcher to bypass the authority of a tribal council. I find it difficult to argue for a moral requirement to obtain consent from the tribal council, but it seems that it serves the long-term interest of science for researchers to recognize the systems of authority of the people with whom they want to work. In other words, even if seeking the consent of the tribal council is not morally required, it will benefit science in the long run because it shows respect for the tribe.