

Research Ethics and Informed Tribal Consent

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And

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Conducting Research in Tribal Communities

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Topics

- **Recent statements about IPR, cross-cultural nursing, anthro, biopharm, CBPR**
- **Extra informed consent needs**
- **Dump data and run – helpfully providing data without understanding cultural consequences**
- **Some bad examples**
- **Some good examples – OSU, Maine**

IRB

Extra effort at
informed
consent and
identifying
potential risks

IPR

Data
ownership;

Publication
rules

Sovereignty

Governmental &
regulatory context;
Cross-cultural
history, psychology,
world view

Triggers

IRB rules arose from abuses and bad outcomes. These are well known. IRB rules for extra effort at informed consent are not quite as clear.

IPR rules from anthropology and indigenous medicinal knowledge of plants are more recent. *Example:*

- **Stories and songs may be ‘owned’ by individuals, yet professors of anthropology make careers of recording and publishing them. Or digging up tribal ancestors.**

Many tribal projects that respond to special federal initiatives last only as long as the federal program because Tribes do not have funds to continue programs once the funding ends.

**I'M FROM THE
GOVERNMENT,
I'M HERE
TO HELP**



NIH funds some health disparities research, but Tribes have to compete for grants with universities according to what the federal government decides the needs are.



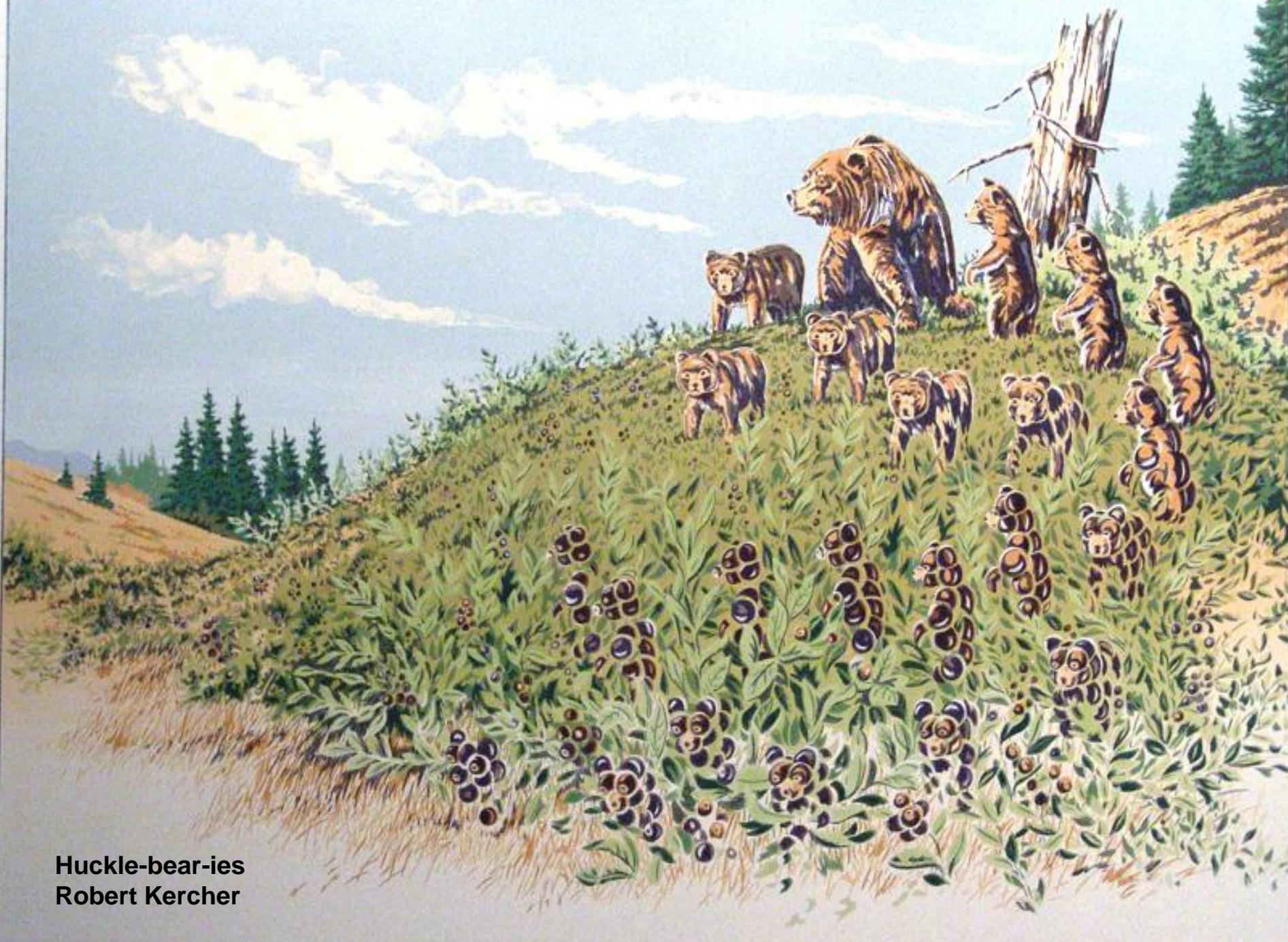
40 years on, reserve mercury poisonings worse

<http://www.thestar.com/news/canada/article/790616--mercury-nightmares-relived>

OTTAWA — Forty years after mercury poisoning gripped remote northwestern Ontario native reserves and captured international attention, the tragic story is still unfolding. Residents, who weren't even born when the province banned fishing on the Wabigoon-English River system in 1970, are showing the effects of mercury poisoning, environmentalists say.

As a result of a 1985 compensation deal, residents of Grassy Narrows and White Dog received \$8,000 and those whose mercury poisoning is acknowledged by the Mercury Disability Board receive only \$250 to \$800 a month.

Health Canada has stopped testing



Huckle-bear-ies
Robert Kercher

Basic Goal

Instead of a message FROM regulators....

Here is how much contamination is in the fish --- you decide how much to eat. You should give up some of your ceremonies. No big deal. You're welcome.

(helping Indian Nations make "healthy" decisions)

Scenarios send a message TO regulators

Here is how much fish we eat --- you make sure it's safe. This is your Trust obligation.

(exercise of sovereignty)

Ethics & Informed Consent

Try It. You'll like it.

TRUST ME

This Won't Hurt a Bit

I know just what you need

Federal Institutional Review Board rules require extra effort to explain benefits and disadvantages of collecting different kinds of data, using various methods, participating in various studies.

This should be a discussion at multiple levels of Tribal authority, not a sales pitch.

The Tribe must have ownership of the project & data.

Extra effort at informed consent

The “Wabanaki Traditional Cultural Lifeways Exposure Scenario” was produced under a Direct Implementation Tribal Cooperative Agreement (DITCA) awarded to the Aroostook Band of Micmac Indians on behalf of the 5 Maine Tribes.

<http://www.epa.gov/region1/govt/tribes/pdfs/DITCA.pdf>

Because tribal leaders were not trained in risk assessment methodology, an additional effort was expended in discussing the overall approach and assumptions with tribal leaders and staff.

Each Tribe (through designated representatives) gained a basic understanding of the process and methods and reviewed both the technical merits and cultural relevancy.

The tribal technical staff that provided direct oversight were also involved at every step, and feedback was continually requested. A variety of discussions and presentations were made, and questions were encouraged.

Identifying Risks unique to Tribal contexts

Informed consent includes a requirement for full disclosure, including the risks, benefits, and uncertainties, as well as the requirement for transparency. (consultants should follow same rules)

Even though human subjects research is not a part of the scenario development, the consequences of underestimating exposure rates could have such an adverse impact on tribal health and sovereignty that an extra level of effort was made.

How the West poisoned Bangladesh

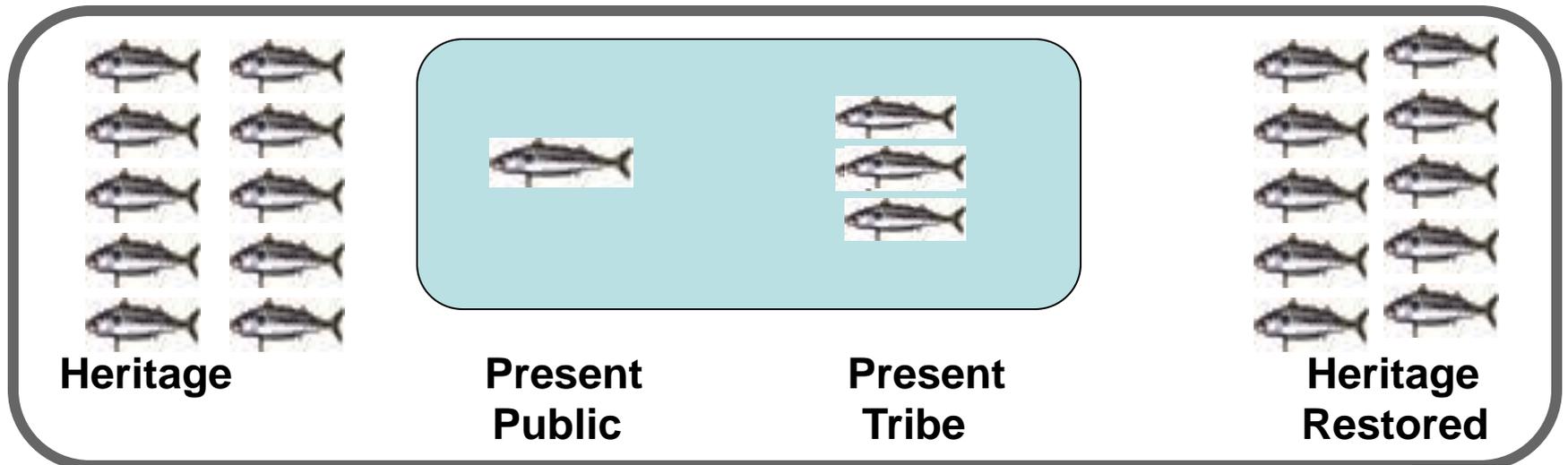
A UN project aimed to help millions escape diarrhea- but it brought them water contaminated with arsenic

Example: Asking the wrong question

The risk of underestimating exposure rates and the risks of an external agency misusing the information can be high.

Whatever amount of fish you eat now is all you ever want to eat.

If you continue to eat contaminated fish you are stupid or illegal. If your risks are too high, you can't use the resource, so someone who can tolerate dirtier conditions gets the land.



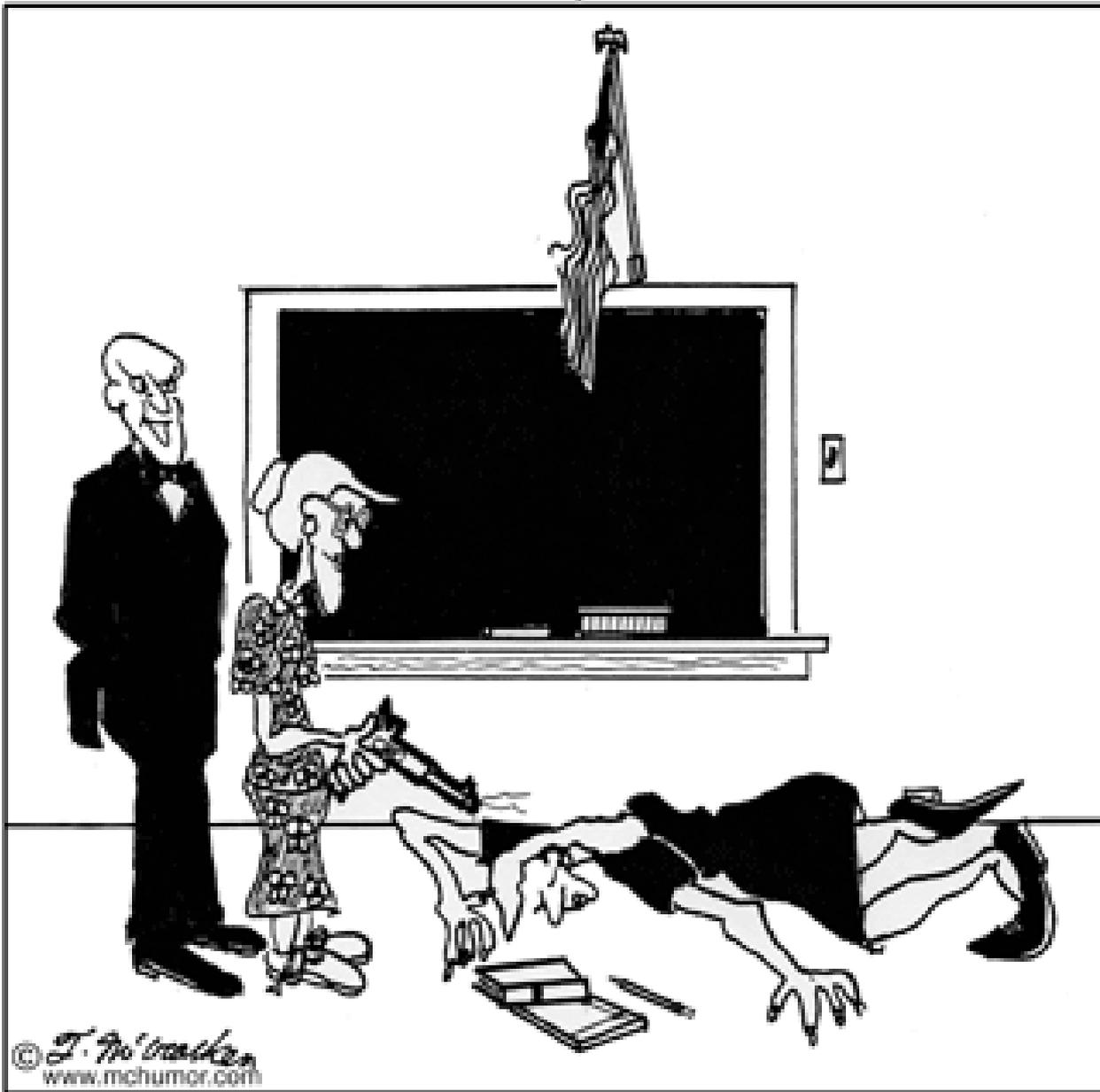
More Context

- **There may be Tribal policies and plans already in motion. The Tribe may not be ready for a particular project.**
- **The Tribe may have higher priorities for the limited staff.**
- **The Tribe may simply choose a different path.**

- **There may be government-to-government (G2G) regulatory negotiations underway. *Example:* Ponca situation – lengthy university research versus immediate regulatory needs.**

Informed Consent – **Scenario Development Example**

- **Informed consent requires full disclosure, including the potential risks, benefits, and uncertainties.**
- **Even though human subjects research was not a part of the scenario development, the consequences of underestimating exposure rates could affect tribal health and sovereignty.**
- **Researcher must understand tribal context and recognize potential risks because tribal leaders are not trained in risk assessment methodology**



**We understand
the need to get
data and
publish.**

**“Enforcing the publish
or perish rule, Dean McWit?”**



"No, it's MY data!"

4/20

Trolling for tribal ideas

**Was discovering vinca alkaloids
good for mankind?
What did the indigenous people
Of Madagascar get?**



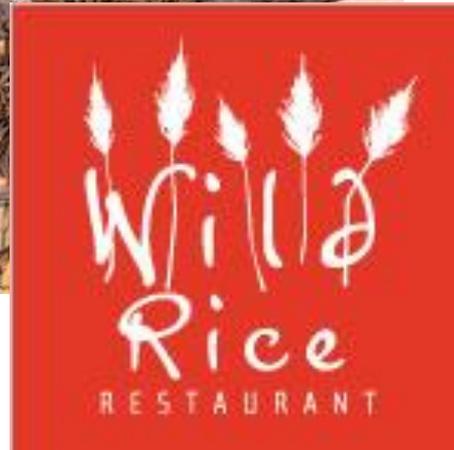
Or is it Biopiracy and Bioprospecting?

**Is it OK to listen to tribes and create first-author
publications for yourself? Or let the Tribe be first
author? Are you speaking for the Tribe or helping
the Tribe speak for itself?**

**We are taught to seek data and new ideas. This can
be quite predatory.**

Echinacea, Wild Rice, & Huckleberries

Ethnobotanical knowledge as an “opportunity” for commercial development. Is this knowledge free for the taking? Apparently so, and thank you for discovering it for us.





Camelia sinensis

Two conventions related to the subject are the Convention on Biological Diversity (CBD) and the agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS). For example, commercialization of various products from Hoodia (from Africa, the source of weight loss drugs), neem (*Azadirachta indica*), wild rice (*Zizania aquatica*), and Basmati rice (from India). Biopiracy is ‘pain for one and the gain for others.’

In India's case, the East India Company, as part of its empire building agenda, employed botanists to compile local knowledge and transfer samples of bio-resources to Britain.



Indigenous Peoples and the Right to Free, Prior and Informed Consent

What is Free, Prior and Informed Consent?

Free is the absence of coercion and outside pressure, including monetary inducements (unless they are mutually agreed to as part of a settlement process), and “divide and conquer” tactics. It includes the absence of any threats or implied retaliation if the results of the decision is to say “no”.

Prior is having sufficient time to allow for information-gathering and full discussion, including translations into traditional languages, before a project starts. It must take place without time pressure or constraints. A plan or project must not begin before this process is fully completed and an agreement is reached.

Informed is having all the relevant information available reflecting all views and positions. This includes the input of traditional elders, spiritual leaders, subsistence practitioners and traditional knowledge holders, with adequate time and resources to consider impartial and balanced information about potential risks and benefits.

Consent is the demonstration of clear and compelling agreement, in keeping with the decision-making structures of the Indigenous Peoples in question, including traditional consensus procedures. Agreements must be reached with the full participation of authorized leaders, representatives or decision-making institutions as decided by the Indigenous Peoples themselves.

http://www.treatycouncil.org/PDFs/FPIC_ENG_072708WEB.pdf

AAA Code of Ethics

The American Anthropological Association (AAA) Code of Ethics also stresses informed consent, working relationships, and respect.

American Anthropological Association (AAA). 1998. Code of Ethics of the American Anthropological Association. June. Available: <http://www.aaanet.org/committees/ethics/ethcode.htm>

WHO and Indigenous peoples

The World Health Organization (WHO) emphasizes “opportunities for the indigenous peoples to review and comment on research findings prior to publication,”

and the opportunity to be associated with the published findings, and either acknowledged in the manuscript or named as co-authors, as appropriate to the contribution made.”

World Health Organization (WHO). 2010. Indigenous People and Participatory Health Research: Planning and Management, Preparing Research Agreements. Available:

http://www.who.int/ethics/indigenous_peoples/en/index9.html

AAAS

The AAAS discusses unpublished information, which is to be treated as the intellectual property of the Tribe unless formal permission is obtained. Many if not all professional scientific societies endorse federal and AAAS principles guiding publication ethics.

Hansen, S.A. 2002. Intellectual Property and Traditional Ecological Knowledge: Institutionally Globalized Biopiracy? Professional Ethics Report. Vol. XV, No. 3, 1-4. Available: <http://www.aaas.org/spp/sfrr/per/per30.pdf>

AAG

The Association of American Geographers (AAG) discusses the paternalistic attitude toward indigenous knowledge being free for the taking, and notes that recognizing intellectual property is a matter of respecting indigenous peoples. They also recognize that tribes should have the opportunity to review and revise drafts of the findings, and strive for relationships of mutual benefit and reciprocity.

Louis, R.P. and Z. Grossman. 2009. Discussion Paper on Research and Indigenous Peoples. Indigenous Peoples Specialty Group of the Association of American Geographers. March. Available:

http://www.pacificworlds.com/ipsg/Discussion_paper.pdf

International Examples

Many other ethics discussions are underway around the world regarding research related to indigenous peoples.

Australian Institute of Aboriginal and Torres Strait Islander Studies. Guidelines for Ethical Research in Indigenous Studies.

Available: www.aiatsis.gov.au/research/docs/ethics.pdf

Davis, M. 2009. Review of AIATSIS Guidelines for Ethical Research in Indigenous Studies: A Discussion Paper – Consultation Draft .

December. Australian Institute of Aboriginal and Torres Strait Islander Studies. Available: www.aiatsis.gov.au/research/ethicsreview.php

RESEARCH WITHOUT PATIENT CONSENT

In 1991, 55% of Havasupai women and 38% of Havasupai men were diabetic. In 1989 Arizona State University and the University of Arizona collected 400 blood samples from tribal members for diabetes research, but those same samples were used for additional unauthorized research on schizophrenia, inbreeding, and population migration. The tribe asserts that research on schizophrenia and inbreeding stigmatizes them and that they would not have authorized any migration research because it conflicts with their religious origin story. The PI did not inform them that she was in the process of, or had previously submitted, a grant application to study schizophrenia among the Havasupai. Nor were they subsequently told that the PI had her assistant surreptitiously examine their medical charts for schizophrenia after operating hours of the local health clinic. The defendants authored 15 publications. ASU whitewashed; court largely decided against Havasupai; the PI is was promoted (UCSD); only a couple technicians were fired.



Havasupai

“We have plaintiffs in this case dying and losing limbs because they are now afraid of doctors.”



Radiological risk from consuming fish and wildlife to Native Americans on the Hanford Site (USA)

Environmental Research

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Rebuttal submitted by the CTUIR and YN

No communication at all

Factually incorrect

Violates agreements and policies

Still unresolved

Material and Data Sharing Agreement CTUIR-OSU Collaboration to Address Tribal Exposures to PAHs and Improve Community Health

Material and Data supplied by CTUIR to OSU or to PNNL, or collected by OSU on behalf of CTUIR, is and remains the property of CTUIR and shall not be shared with third parties without the written permission of CTUIR. Participant data shall not be sold or used, internally or externally, for any purpose not directly related to the scope of work defined in this agreement without the written permission of CTUIR.

All publications and presentations developed using materials or data collected under this Agreement must be presented to Stuart Harris, Director of the Department of Science and Engineering, CTUIR for review and approval prior to dissemination.

CBPR

Is an orientation to research which equitably involves all partners in the research process and recognizes the unique strengths that each brings.

http://obssr.od.nih.gov/scientific_areas/methodology/community_based_participatory_research/index.aspx

<http://www.researchethics.org/articles.asp>

Messages

Partnerships Welcome

- Environmental health, toxics, native plants, green engineering, geophysics, climate change.
- Dept is entirely grant-funded.

CTUIR and other native students

- Stay in school, finish your degree, then come work for us (depending on grants).

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