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## Commentary

# Power, rights, respect and data ownership in academic research with indigenous peoples

Susan Moodie

Johns Hopkins University, Division of Environmental Health Engineering, 615 North Wolfe Street, Baltimore, MD 21205, USA

In some cases, environmental research raises ethical and legal issues when indigenous peoples are involved. Two recent events underscore the persistent and appalling disconnect between the actions of academic researchers and the expectations and rights of indigenous people participating in research around the world. This provides an important opportunity to examine these issues in a context of research relevant to papers submitted to this journal.

In the first case, the Havasupai Indians of Arizona sued Arizona State University (ASU) concerning health studies on gene environment interactions. The Havasupai Nation had given consent to ASU researchers to investigate the potential for genetic relationships in high rates of diabetes in their community, but without consultation or permission the researchers published DNA results on mental health, inbreeding and the ancestral origins of the tribe. The second example occurred within this journal. A study on the radiological risk of fish and wildlife consumption was published in *Environmental Research*, this contravened the agreed upon conditions of a data protocol agreement between Washington State and native sovereign governments as the Yakama Nation and the Confederated Tribes of the Umatilla Indian Reservation (CFTUIR). The Washington tribes had not been involved in the research development, had no knowledge of the research taking place and had not given consent to conduct the research or publish.

While neither situation is new or unique with respect to research involving aboriginal peoples, each is ethically, legally – and therefore academically – unacceptable. Both of these examples demonstrate the hegemonic approach of most academic research that persists in objectifying indigenous people as passive subjects of research rather than as people with inherent power and collective rights in deciding how research should be developed, carried out, analyzed and reported. I call attention to this issue to urge researchers and publishers alike to re-think outdated assumptions and approaches to conducting and publishing research in hopes that the academic community becomes more conscious of the potential impacts of such neo-colonial approaches to research and shift towards a more egalitarian,

participatory research process that can strengthen the quality of research for both researchers and indigenous peoples.

I will not be focusing upon the particulars of these two examples highlighted above, which have been documented elsewhere. As reported in the *New York Times* (April 21, 2010), the Havasupai won their court case, conducted a ceremony when their blood samples were returned to the community, and will receive a settlement of \$700,000. In the second case, the correspondence printed in *Environmental Research* from CFTUIR and the Yakama Nation clearly articulates the ethical and discriminatory outcomes resulting from lack of consent in research decisions, for which the researchers have acknowledged responsibility and apologized for. Instead, I will discuss the continued lack of action to ensure ethical and responsible conduct in research and publication and to evaluate some strategies for change.

Importantly, what does it mean to be “indigenous people” and why is this relevant to a research context? The United Nations has not adopted an official definition of “indigenous people” due to their diversity worldwide ([International Working Group on Indigenous Affairs, 2006](#)). However, included in most descriptions of indigenous is as follows: (1) self-identification as indigenous with historical continuity pre-colonization; (2) strong environmental and geographic links; (3) distinct languages, cultures, beliefs and (4) social, economic and political systems outside the dominant society ([International Working Group on Indigenous Affairs, 2006](#)). Colonialism has impacted all indigenous populations, generally to their detriment. The legacy of colonization has led to the reality that indigenous people “remain on the margins of society: they are poorer, less educated, die at a younger age, are much more likely to commit suicide, and are generally in worse health than the rest of the population ([United Nations, 2005](#))”. In the words of Waziyatawin, “our bodies clearly have not benefited from colonization ([Waziyatawin, 2005](#)).” Though not acknowledged in all countries, as part of sovereign nations, the leadership of indigenous communities should be respected as representatives of self-determined governments who are responsible for making the decisions that affect their members. This includes the determination of what research is relevant and acceptable to their communities, and how it should be conducted. In particular, because many of these indigenous communities are under-resourced, priorities need to be carefully chosen and well defined to secure the maximum benefit for the community’s health.

Exploitation through research practices that compensate participants also needs to be avoided through this process. These principles are consistent with those of community-based participatory research (CBPR) and further elaboration will be provided (Israel et al., 2005; Laveaux and Christopher, 2009).

A key hindrance in conducting research responsibly with indigenous peoples is the divide in how Western scientists view their autonomy in conducting research and the protocol expectations of indigenous peoples. The term “protocol” in relation to indigenous research refers to the set of conditions agreed upon as rules of conduct for the researcher and involvement of indigenous people in decisions and interpretations made at every phase of the research, as will be discussed further, from identifying research needs through to communicating results (Assembly of First Nations, 2007). Hypothesis driven research, common in biomedical and health research, has not done well at incorporating community priorities or perspectives into the methodological design of studies (Arbor and Cook, 2006). Common practice in epidemiological design rewards bias reduction, but this may be viewed as disrespectful to the autonomy of indigenous communities. Research subjects are intended to be recruited and studied anonymously, and rarely are results given back to the participants. While there is a need to respect personal privacy in research, there is a tension with indigenous communities’ expectation to more directly benefit from participating in the research. Allowing the communities to set priorities raises concerns about biases being introduced to the study. However, community-driven research has proven to be more reliable when methods are more closely aligned with indigenous community priorities, such as community-based participatory research. Another way to conduct responsible research practices is benefit sharing between researchers and communities; this strategy is gaining attention internationally (Koppers, 2000; Weijer, 2000, 1999; Weijer et al., 1999), and remains extremely important in the case of indigenous communities (Christopher, 2005; Burhansstipanov et al., 2005; National Aboriginal Health Organization, 2007).

Community-based participatory research (CBPR) is based on the following key principles: (1) recognize the community as a unit of identity; (2) build on the strengths and resources of the community; (3) facilitate collaborative partnerships in all phases of the research; (4) integrate knowledge and action for mutual benefit of all partners; (5) promote a co-learning and empowering process that attends to social inequalities; (6) involve a cyclical and iterative process; (7) frame research in positive perspectives and integrated with ecosystem based understanding and (8) disseminate findings and knowledge gained to all partners (Israel et al., 2005). Adherence to these principles is critical to responsible research practices with indigenous communities.

LaVeaux and Christopher identify additional principles which are specific to CBPR research with indigenous communities: (1) acknowledge historical experiences of the community with research that has not followed appropriate protocols; (2) recognize and respect tribal sovereignty; (3) recognize tribal and community membership as defined by the community (i.e. may include non-native or non-status individuals); (4) understand tribal diversity and the implications for research of different communities having their own customs; (5) plan for extended timelines to allow for appropriate process for community participation; (6) recognize gatekeepers; (7) prepare for leadership turnover; (8) interpret data within the cultural context and (9) use indigenous ways of knowing (Laveaux and Christopher, 2009). While detailed explication of these principles is beyond the scope of this commentary, these principles lay the groundwork for approaching research in a different fashion than current methods

in academic research, which can build trust and level out inequities between indigenous communities and researchers.

In designing and conducting research, “the who and the how of participation is never innocent or purely process driven, but rather always power-full (Berg et al., 2007)”, and these power dynamics should be identified to provide a more equitable approach to conducting research. There has been a long history of researchers flying in and leaving without any attempt to work respectfully with community members. However, this type of “helicopter research” is no longer acceptable to indigenous peoples. Increasingly, indigenous communities are developing their own indigenous research protocols for ethical research practices. In Canada, the Assembly of First Nations<sup>1</sup> has developed O.C.A.P., *Ownership, Control, Access and Possession: First Nations Inherent Right to Govern First Nations’ Data* (Assembly of First Nations, 2007), which is accompanied by the National Aboriginal Health Organization’s *Considerations and Templates for Ethical Research Practices* (National Aboriginal Health Organization, 2007). These provide a framework to “counteract the harm done to First Nations by research that failed to respect the importance of understanding the First Nations way of knowing while treating First Nations as specimens rather than people with specific human rights (Assembly of First Nations, 2007).”

A brief description of OCAP terms will be helpful to this discussion. “Ownership” describes the collective nature and inherent rights of how a First Nation’s cultural knowledge, data and information are owned. “Control” refers to “all aspects of information management including resources, policy development and implementation, review processes, formulation of conceptual frameworks, data management, etc. (Assembly of First Nations, 2007).” “Access” is the right to manage and make decisions regarding access to First Nations’ collective information (Assembly of First Nations, 2007). “Possession” is a mechanism to assert and protect ownership and control management through physical possession of data or samples. These criteria need to be further refined based on the distinct culture and protocols of each indigenous community and how the members choose to express their self-governance. The OCAP research protocol states, “Failure to incorporate the principles of OCAP is both unethical due to potential harm to the nation and unlawful as entrenched in First Nations legal right to self-governance.”(p. 4) (Assembly of First Nations, 2007).

Many researchers may balk at the idea that they are not the ones entitled to the principles of ownership, control, access and possession, the principles of OCAP, as researchers have been conditioned to believe that they own the data they collect.

Consider as an example the management of biological samples. For many indigenous people, this is a highly contentious issue. For many indigenous people, any part of themselves is sacred, and not just a blood or tissue sample, “it is part of a person, it is sacred, with deep religious significance, it is part of the essence of a person (Harry et al., 2000).” One proposed approach offers the view that samples are the continued property of the donor or community and are on loan to the researcher who is obligated to act as a respectful steward and hold the sample for the purpose for which consent has been given. If this approach had been followed in the incidents cited at the initiation of this commentary, the Havasupai DNA would not have been inappropriately analyzed and the Washington tribe’s data sharing protocol would have been followed (Arbor and Cook, 2006). This represents a shift from standard research practices, and allows for trust to be built

<sup>1</sup> In this section, I will use the term “First Nation” instead of “indigenous” out of respect for the preferred terminology use in Canada, the terms are synonymous for the purposes in this paper.

into a study from the outset, defines clear community data analysis protocols, including involvement in interpreting analysis from indigenous perspectives.

Integration of indigenous research ethics needs to occur on all levels of the research and academic infrastructure. For example, Institutional Review Boards (IRB) generally but not always requires a letter confirming the indigenous community's agreement to participate in research. There has been a failure to ensure research agreements were appropriately followed throughout the research. To determine if the initially proposed indigenous research protocols were carried out in full, a review of indigenous community based agreements upon completion of the research is needed to provide adequate tracking in the long term. I would further propose that IRBs should be more rigorous upfront in their requirements. A letter of agreement cannot be substituted for a thoroughly detailed indigenous research protocol developed in partnership with indigenous communities. These are different. One can have a full letter of agreement without a protocol developed in partnership, and vice versa. Similarly, publishers should specifically require that authors whose research involved indigenous people as to what indigenous research protocols were followed, as merely having IRB approval is clearly insufficient in this context. Research without clearly defined indigenous research protocols involving indigenous communities should neither receive IRB approval nor be considered worthy of publication.

Funding institutions should recognize that indigenous research has special ethical, and their engagement is needed to support changes in research practices. In Canada, the Social Sciences and Humanities Research Council (SSHRC), one of three agencies that constitute the federal funding body that promotes and supports university-based research and training, has developed aboriginal research funding programs based on "strong evidence of the need to shift away from research on and for Aboriginal<sup>2</sup> peoples, to research by and with Aboriginal peoples (Social Sciences and Humanities Research Council, 2010)." In Canada, the process of full review involves two steps with the first step being project approval by the Relevance Committee. The Relevance Committee assesses "whether or not strong research partnership agreements, involving both Aboriginal and academic communities, are likely to emerge" and also identifies if "in planning the research, the applicant has taken care to identify and respect relevant community research protocols and Aboriginal knowledge systems (Social Sciences and Humanities Research Council, 2010)." Following approval of the Relevance Committee, the Adjudication Committee, an interdisciplinary peer-review committee assesses the scholarly merit of the proposal (Social Sciences and Humanities Research Council, 2010). Additionally, the evaluation criteria for adjudication take into consideration the quality of the training plan, the career stage and promise of the researcher, and make allowances for past circumstances that had impeded research and for smaller institutions which may be under-resourced (Social Sciences and Humanities Research Council, 2010). This is important to improve access and equitability for indigenous researchers who, being from remote and

under-resourced communities, are more likely to have been disadvantaged in their educations and institutions they attended. This is a small step towards supporting equitable review and funding of research that identifies methods appropriate for indigenous communities.

In summary, recognizing the fundamental human rights of indigenous people to self-determination as members of sovereign nations carries a responsibility for current researchers to act ethically and respectfully in their roles. Claims that legal requirements and protocols were not known are not acceptable; it is the responsibility of the researcher to ensure their development in accordance with principles comparable to OCAP. I extend this call to action to other parts of the academic infrastructure, funding mechanisms, researchers, IRB processes and publishers. All parties must re-examine current practices and assumptions to revise indigenous research protocols and act responsibly in the context of research driven by indigenous people for the purpose of improving health within their communities.

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<sup>2</sup> For this paper, use of "Aboriginal" in the documents cited is synonymous with "indigenous".