

DISCUSSION PAPER

Lessons for ABS: Academic Policies, Community Protocols and Community-level PIC

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In applying prior informed consent (PIC) to access and benefit-sharing (ABS) policies, it is important and useful to remind ourselves of the origins of PIC, its historical situatedness and evolution, and its current application to contexts for which it was not originally conceived. PIC is a principle that is deeply embedded in contemporary law and ethics. It is rooted in respect for individual autonomy and autonomous choice. In ethics, PIC evolved from the concept of “voluntary consent”, which emerged in biomedical research ethics in the 1940s (i.e., the Nuremberg Code) in response to human atrocities committed against inmates of concentration camps by Nazi scientists in the name of research.

PIC was originally conceived (in ethics) in reference to the *individual* as a protection from *physical* harm, but it is increasingly being extended to *collective* and *non-physical* contexts. Within Canada, the most notable collective application of PIC is to research and development involving Aboriginal communities. The academic research community has struggled with the conception, application and implementation of community PIC in recent years, and it remains a hotly debated subject. When such a deep disparity exists about a term that is being used more and more widely, it can be helpful to take a step back to understand what it is that we don't understand. This paper will (i) explore how community-level PIC is currently portrayed in academic research policies and how it is understood - or misunderstood - in scientific research, and (ii) attempts to unearth lessons for new ABS policy development.

Within Canada, all university-sponsored research involving humans must abide by a national ethical standard called the *Tri-Council Policy Statement for Research Involving Humans*, which was developed in 1998.¹ PIC (referred to as “free and informed consent”) is a fundamental principle of this policy; researchers are required to demonstrate that individuals who participate in research do so without undue influence or coercion, understanding the purpose, risks and benefits involved.

PIC is conceptualised as an *ongoing* process that begins before research is initiated and extends throughout the research process. Further, the *Tri-Council Policy Statement* requires that participant consent can be “withdrawn at any time” (Section 2.2, Paragraph 1), meaning research participants can withdraw their participation from the research and may also be entitled to withdraw their contributions up until that time. Usually evidence of PIC is written, for example a consent form signed by the participant before research begins. In certain cases, PIC could be given verbally or in some other form deemed appropriate to the context. At least in theory, the quality of the consent is considered more important than the form it takes, allowing for culturally-appropriate forms and processes. In practice, however, federal

¹ Policy available at <http://www.pre.ethics.gc.ca/english/policystatement/policystatement.cfm>

III. Specific Issues for consideration in the elaboration of the IR:
Indigenous Peoples-Community-level PIC for accessing TK and genetic resources

granting councils and university administrations encourage a written form of consent likening PIC to a contractual agreement between researcher and the researched, evidenced by sign-off at the onset of research. A sharp contrast (even irony) exists, therefore, between the intended philosophical rationale behind PIC (i.e., an ongoing process) and the ways it is usually practiced (i.e., upfront sign-off).

Section 6 of the *Tri-Council Policy Statement* is specific to research involving Aboriginal peoples. It explicitly acknowledges that “some research involving aboriginal individuals may also involve the communities or groups to which they belong” and that “aboriginal peoples have distinctive perspectives and understandings embodied in their cultures and histories ...[and] a unique interest in ensuring accurate and informed research concerning their heritage, customs and community” (Section 6A, Paragraph 6). The central issue raised in Section 6 is determining “when it is legitimate for researchers to interview individuals in their own right as individuals, without regard to the interests of the group as a whole and without seeking permission from any group authority or spokesperson or, conversely, when the approval of the community as a whole should be required.” (Section 6A, Paragraph 10).

The *Tri-Council Policy Statement* currently offers little specific guidance in resolving the issue of collective PIC in an Aboriginal context and is widely recognized as seriously inadequate. An extensive revision for Section 6 is in progress. Meanwhile, the policy currently advises researchers to be familiar with several other existing guidelines for research on Aboriginal communities.² The key point to note here is that the current national ethics standard in Canada essentially *defers* to other existing documents that have been created by Aboriginal groups or institutions, organizations, and societies working closely with Aboriginal groups.

In addition to various institutional guidelines, many Aboriginal groups in Canada (and elsewhere) have developed their own local guidelines or protocols for research.³ Among other things, such as the need for reciprocal trust and respect, these outline community expectations about access to and use of their traditional knowledge and related biological resources by outsiders. Community protocols are increasingly being used in defining

² The recommended documents are: Inuit Circumpolar conference. *Principles and Elements for a Comprehensive Arctic Policy*, Alaska, Greenland, Canada; Council for International Organizations of Medical Sciences. *International Guidelines for Ethical Review of Epidemiological Studies*. Geneva: WHO, 1991; National Health and Medical Research Council of Australia, *Guidelines of Ethical Matters in Aboriginal and Torres Strait Islander Health Research*. Canberra: NHMRC, 1991; American Anthropological Association, *Statement on Ethics: Principles of Professional Responsibility*, Adopted by the Council of the American Anthropological Association, May 1971; American Public Health Association Task Force. *National Arctic Health Science Policy*. Washington, D.C.: APHA, 1984; American Indian Law Center. *Model Tribal Research Code*. Albuquerque, 1994; and U.S. Interagency Arctic Research Policy Committee, *Principles for the Conduct of Research in the Arctic*. Arctic Research of the United States 1995;9 (Spring):56-57; Association of Canadian Universities for Northern Studies, *Ethical Principles for the Conduct of Research in the North*, Ottawa: ACUNS, 1982, reprinted, 1988. Royal Commission on Aboriginal Peoples. Appendix B: *Ethical Guidelines for Research*. Ottawa: RCAP, 1993.

³ Some Canadian examples are: *Code of Ethics for Researchers Conducting Research Concerning the Ktunaxa Nation*; *Namgis First Nation Guidelines for Visiting Researchers/Access to Information*; *Tl'azt'en Nation Guidelines for Research in Tl'azt'en Territory*; *Akwesasne Nation Protocol for Review of Environmental and Scientific Research Proposals*; *Standard of Conduct for Research in Northern Barkley and Clayoquot Sound Communities*.

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relationships between indigenous communities and university researchers, in some cases as a defensive response to the imposition of research, and in other cases as a way to actively encourage research and economic development opportunities. Community-level processes for obtaining consent from Indigenous peoples (e.g., customary laws and community protocols) must be given serious consideration in new PIC policy development, as should the role of tribal committees for reviewing research involving specific indigenous peoples and their associated cultural knowledge and traditional resources.

At the same time, some issues need to be kept in mind. Many community protocols describe a process for obtaining PIC that includes approval by a band council, tribal council, council of Elders, or tribal ethics committee, in addition to the consent of the individual participant. A template consent form is sometimes included. Thus “community-level PIC” in some protocols may be equated with a gate-keeping function provided by a sub-group within the Aboriginal community. Sometimes this is a respected political body, group of Elders or other community members, but sometimes this is a political body that is divorced from traditional practices and/or not supported by the traditional knowledge holders of the community. In these cases, important questions internal to the community may emerge, such as “who has the right to speak for who” and “who can speak about what”?

Some critics have argued in such cases that instead of creating a collective consent process, a “power over” situation emerges within the Aboriginal community, thereby taking away from individual autonomous choice. This adds a new spin to the key question framed in Section 6 of the *Tri-Council Policy Statement*, essentially turning it on its head. That is, from a community member’s perspective, the question may become “when it is legitimate for *participants to be interviewed* in their own right as individuals, without regard to the interests of the group as a whole and without seeking permission from any group authority or spokesperson or, conversely, when the approval of the community as a whole should be required.” Resolve of this question through internal decision-making processes is pre-requisite to granting community-level PIC to those outside a community.

While the principle of community-level PIC is a vital element of any new ABS policy, for its implementation to meet the intention, the concept must be vigorously discussed until it is more uniformly understood and agreed by users and providers, both indigenous and non-indigenous. Universities, governments and others who wish to interact “institution-to-institution” with indigenous communities must realize that indigenous communities are not made up of homogenous groups of individuals who always agree on internal protocols and processes. Many indigenous communities will need to be enabled (through provision of time, funds, access to information, building of expertise) to *define for themselves* the concept of community-level PIC and the internal process to achieve it, before an external process can be codified. Even within a given nation, such as Canada, this will undoubtedly lead to a suite of different answers rather than a one-size-fit-all solution. An effective and equitable ABS policy must be able to accommodate and support this complexity.