
**Draft 2nd Edition of the
*Tri-Council Policy Statement: Ethical Conduct for
Research Involving Humans (TCPS)***

REVISED

*Comparison: November 2009
and December 2009*

CHAPTER 9

Research Involving Aboriginal Peoples in Canada

Comment Period Closing Date: March 1, 2010



Interagency Advisory Panel
on Research Ethics

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Foreword

The Interagency Advisory Panel on Research Ethics (the Panel) is pleased to announce the early release of the revised draft version of Chapter 9 (“Research Involving Aboriginal Peoples in Canada”) of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS) for further public comment. The early release of this chapter is provided in response to requests made by a number of individuals and groups in the Aboriginal community and the research community at large.

A Harmonization Committee was established in July 2009 to clarify areas of correspondence and divergence between Chapter 9 and the Canadian Institutes of Health Research (CIHR) *Guidelines for Health Research Involving Aboriginal People*. The Panel gratefully acknowledges the collaborative efforts of representatives from the CIHR Ethics Office and the Institute of Aboriginal Peoples’ Health (IAPH), as well as representatives from the Social Sciences and Humanities Research Council of Canada (SSHRC) and the Natural Sciences and Engineering Research Council of Canada (NSERC). All provided valued input to ensure that the needs and perspectives of researchers from their respective fields were considered in the revision.

Written comments on the revised draft Chapter 9 will be accepted until March 1, 2010. National Aboriginal organizations are invited to consult with their constituencies. First Nations, Inuit and Métis communities, and researchers engaged with them, are especially encouraged to respond. Comments received from the three Agencies’ research communities and their community partners will also be integral to the finalization of Chapter 9 and associated provisions in the TCPS as a whole.

The complete revised draft 2nd edition of the TCPS will be made public in December 2009. A final draft 2nd edition of the TCPS will be provided to the three Agencies for review and approval in the Spring of 2010.

Please include your name with your comments. It is the Panel’s intention to post all comments on the revised draft 2nd edition of the TCPS, including Chapter 9, on the Panel’s website after the closing of the comment period. If you do not wish to have your comments posted, please indicate that clearly in your submission.

For additional information on the Panel’s Aboriginal Research Ethics Initiative (AREI), visit www.pre.ethics.gc.ca/eng/policy-politique/initiatives/reports-rapports/arei-iera/.

Thank you for your continued engagement and for contributing to the revision of the TCPS.

Draft: Chapter 9

RESEARCH INVOLVING ABORIGINAL PEOPLES IN CANADA

INTRODUCTION

Note: A draft of Chapter 9 was released in November 2009. The version below was revised. To view the November 2009 version as well as a version showing where changes were made, please click on the following link: www.pre.ethics.gc.ca/eng/policy-politique/initiatives/reports-rapports/arei-iera/.

Introduction

The Aboriginal and treaty rights of Aboriginal peoples of Canada, including the Indian (First Nations), Inuit and Métis peoples, ~~which~~ of Canada, were recognized and affirmed in the Constitution Act, 1982, ~~create~~.¹ This affirmation implies an obligation on public institutions ethical duty for those involved in research to acknowledge and support the desire of ~~First Nations, Inuit and Métis~~ Aboriginal Peoples to maintain their collective identities and the continuity of their cultures.

This chapter acknowledges the unique status of the Aboriginal peoples of Canada. It interprets how the value of respect for human dignity and the core principles of respect for persons, concern for welfare, and justice, as articulated in Chapter 1 (“Ethics Framework”) apply to research involving Aboriginal peoples. It accords respect to Indigenous knowledge systems by ensuring that distinct world views are represented wherever possible in planning and decision-making, from the earliest stages of conception and design of projects through to analysis and dissemination of results. It affirms Aboriginal rights, interests and responsibilities as reflected in community customs and codes of research practice in order to better ensure balance in the relationship between researchers and participants and mutual benefit in researcher-community relations. The purpose of this chapter specifically, and the Policy in general, is to provide guidance to researchers on ethical conduct in research involving Aboriginal peoples. Neither this Policy nor this chapter are meant to reflect or introduce any change to current Government of Canada policy with respect to the issues discussed herein.

Indian peoples commonly identify themselves as “First Nations.” The desire to conserve and develop knowledge specific to First Nations, Inuit and Métis communities, and to benefit from ~~modern~~ contemporary applications of traditional knowledge, is a motivating force in community initiatives to assume a decisive role in research. The guidance provided in this chapter is based on the premise that engagement with community is an integral part of ethical research involving Aboriginal peoples. While continuing to respect individual autonomy, this Policy acknowledges the role of community in shaping the conduct of research, in particular, research that affects First Nations, Inuit and Métis peoples. In light of

37 the diversity within and between First Nations, Inuit and Métis communities, and the
38 ongoing development of community codes of research practice by these communities at the
39 local, regional and national level, ethical review of a proposed project must be attentive to
40 its specific context.

41 This chapter has drawn on prior work, both within Canada and internationally, that
42 recognizes the rights, interests and responsibilities of Aboriginal peoples participating in and
43 affected by research endeavours. Some of that work has been done by the three agencies
44 responsible for this Policy. In particular, the Canadian Institutes of Health Research (CIHR)
45 and its Institute of Aboriginal Peoples' Health have engaged in extensive dialogue with
46 community partners to develop CIHR *Guidelines for Health Research Involving Aboriginal*
47 *People* (2007). The Social Sciences and Humanities Research Council (SSHRC) and the
48 Natural Sciences and Engineering Research Council (NSERC), likewise, have developed
49 guidelines applicable to programs targeted at research involving Aboriginal people and
50 issues. Aboriginal entities at local, regional and national levels have published and
51 implemented codes governing research practice, including ethical protections, that
52 emphasize collective rights, interests and responsibilities.

53 This Policy provides guidance for research involving humans, as defined in Chapter 2
54 (“~~Scope and Approach~~”). Guidelines applicable to particular programs, research domains
55 and community settings may elaborate on processes set out herein, or may address ethical
56 concerns of broader scope. Researchers and research ethics boards (REBs) are advised to
57 consult reference documents that apply to their research undertaking. Examples of relevant
58 resources are listed at the end of this chapter.

59 **A. Key Concepts and Definitions**

60 ~~This~~ For the purposes of this Policyⁱⁱ, ~~this~~ chapter uses the following key concepts:

- 61 ▪ Aboriginal peoples: ~~A – a term used in the Constitution Act, 1982,~~ⁱⁱⁱ referring
62 collectively to Indian (~~First Nations~~), Inuit and Métis peoples of Canada, whose
63 existing Aboriginal and treaty rights are recognized and affirmed and protected.
64 Indian peoples commonly identify themselves by traditional names such as
65 Mi'kmaq, Dene or Haida, and as First Nations. For the purposes of this Policy,
66 ~~this~~ the term “Aboriginal” includes persons of First Nations, Inuit or Métis origin –
67 regardless of where they reside and whether or not they have status on an official
68 register. The term “Aboriginal” glosses over the distinctions among First Nations,
69 Inuit and Métis peoples, who have their own ~~distinct~~ histories, cultures and
70 languages, so an attempt has been made to limit use of the term in this Policy to
71 instances where a global term is appropriate.
- 72 ▪ Aboriginal rights, interests and responsibilities: ~~For – for~~ for the purposes of this Policy,
73 ethical obligations are more broadly construed than the legal definition of Aboriginal
74 and treaty rights. The term “responsibilities” is consistent with Aboriginal
75 worldviews that include multi-generational obligations to ancestors and future
76 generations.

77 | ▪ ~~Community: A term used to describe – describes~~ a collectivity with shared identity
78 | or interests that has the capacity to act or express itself as a group. In this Policy, a
79 | community may be territorial, organizational or a community of interest. Territorial
80 | communities have governing bodies exercising local or regional jurisdiction, for
81 | example, members of a First Nation resident on reserve lands. Organizational
82 | communities have explicit mandates and formal leadership. In both territorial and
83 | organizational communities, membership is defined and the community has
84 | designated leaders. Communities of interest may be formed by individuals or
85 | organizations who come together for a common purpose or undertaking, such as a
86 | commitment to conserving a heritage language. These are informal communities;
87 | whose boundaries and leadership may be fluid and less well-defined. They may exist
88 | temporarily or over the long term.

89 | An individual may belong to multiple communities, both Aboriginal and non-
90 | Aboriginal, for example, as a member of a local Métis community, a graduate
91 | students’ society, and a coalition in support of Aboriginal rights. For the purposes of
92 | research, how an individual defines which of his or her community relationships are
93 | most relevant will likely depend on the nature of the particular research project being
94 | proposed.

95 | ▪ ~~Community engagement: Community engagement is –~~ a process that establishes
96 | interaction between a researcher or research team and the Aboriginal community
97 | relevant to the research project. It signifies a collaborative relationship between
98 | researchers and communities, although the degree of collaboration may vary
99 | depending on the community context and the nature of the research. The engagement
100 | may take many forms, including: – consent from formal leadership to conduct
101 | research in the community; joint planning with a responsible agency; commitment
102 | to a partnership formalized in a research agreement; or dialogue with an advisory
103 | group expert in the customs governing the knowledge being sought. The level of
104 | engagement may range from information sharing to active participation and
105 | collaboration to empowerment and shared leadership of the research project.
106 | Communities may also choose not to engage actively in a research project, but
107 | simply to acknowledge it and register no objection to it.

108 | ▪ ~~Indigenous knowledge is the term in common usage internationally to refer to –~~ the
109 | knowledge held by Indigenous peoples who, in Canada, may be referred to as
110 | Aboriginal. Indigenous knowledge is usually described as holistic, involving body,
111 | mind, feelings and spirit. Knowledge is specific to place, transmitted orally and
112 | rooted in the experience of multiple generations. Indigenous knowledge is expressed
113 | in symbols, arts, ceremonial and everyday practices, narratives and, especially, in
114 | relationships. Indigenous peoples value their relationship with the land as a living
115 | entity that reveals the way to living a good life. Spirituality expressed in traditional
116 | or Christian practices, relationships with ancestors and responsibilities to
117 | comingfuture generations are integral to the worldworld view of many Aboriginal
118 | peoples.

119 Indigenous knowledge has gained recognition as a resource of potential benefit to
120 modern society – for example, through traditional techniques of sustaining
121 environmental systems in balance with human usage or knowledge of plant life for
122 agricultural, medicinal and cosmetic purposes. It includes traditional knowledge
123 received from past generations and innovations transmitted to subsequent
124 generations.

125 **B. Interpreting the Ethics Framework in First Nations, Inuit and Métis** 126 **Aboriginal Contexts**

127 Chapter 1 (“~~Ethics Framework~~”) identifies three principles as expressions of the core ethical
128 value of respect for human dignity: respect for persons, concern for welfare, and justice.
129 The three core principles are interpreted in this chapter as follows:

130 **Respect for persons** is expressed principally through securing the voluntary, informed
131 consent of research participants. First Nations, Inuit and Métis concerns for their continuity
132 as peoples with distinctive cultures and identities have increasingly led to the development
133 of codes of research practice that address concerns arising from their worldworld views.
134 Aboriginal codes of research practice thus go beyond the scope of ethical protections for
135 individual participants, and extend to the interconnection between humans and the natural
136 world, as well as obligations to maintain and pass on to future generations knowledge
137 received from ancestors and innovations devised in the present generation.

138 Historically, the well-being of individual participants has been the focus of research ethics
139 guidelines. In this Policy, the principle of **concern for welfare** is broader, requiring
140 consideration of participants and potential participants in their physical, social, economic,
141 and cultural environments. This Policy acknowledges the important role of Aboriginal
142 communities in promoting collective rights, interests and responsibilities that also serve the
143 welfare of individuals.

144 Aboriginal peoples are particularly concerned that research should enhance their capacity to
145 maintain their cultures, languages and identities as distinct peoples and to facilitate their full
146 participation in and contribution to Canadian society. The interpretation of concern for
147 welfare in First Nations, Inuit and Métis contexts may therefore place strong emphasis on
148 collective welfare as a complement to individual well-being.

149 **Justice** may be compromised when a serious imbalance of power prevails between the
150 researcher and participants. Resulting harms are seldom intentional but nonetheless real for
151 the research participants. In the case of Aboriginal peoples, abuses stemming from research
152 have included: misappropriation of cultural heritage such as songs, stories and artefacts;
153 devaluing of Indigenous knowledge as primitive or superstitious; violation of community
154 norms regarding the use of human tissue and remains; and dissemination of information that
155 misrepresented or stigmatized whole communities.

156 Where the social, cultural or linguistic distance between the community and researchers
157 from outside the community is significant, the potential for misunderstanding is likewise

158 significant. Engagement between the community involved and researchers, initiated prior to
159 recruiting participants and maintained over the course of the research, can enhance ethical
160 practice and the quality of research. Taking time to establish a relationship can promote
161 mutual trust and communication, identify mutually beneficial research goals, define
162 appropriate research collaborations or partnerships, and ensure that the conduct of research
163 adheres to the [core](#) principles of justice, respect for persons and the concern for welfare of
164 the collective, as understood by all parties involved.

165 **Research Involving Indigenous Peoples in Other Countries**

166 [“Indigenous peoples”](#) is a term used in international discourse, roughly equivalent to the
167 umbrella term [“Aboriginal peoples”](#) in Canada. [For the purposes of this Policy, the](#)
168 [following are considered to be among the characteristics that identify them.](#) Indigenous
169 people are the descendants of those who inhabited a country or a geographical region prior
170 to the time when people of different cultures or ethnic origins arrived and established
171 dominance through conquest, occupation or settlement. They display resolve to maintain and
172 adapt their heritage and historical links to their territories and associated natural resources.

173 Although the present chapter addresses research involving Aboriginal peoples in Canada,
174 researchers, ~~research ethics boards (REBs)~~, research participants and the research
175 community at large may find the guidance articulated here useful when undertaking research
176 or reviewing a proposal involving Indigenous peoples in other countries or ethno-cultural
177 groups who endorse collective decision-making as a complement to individual consent.
178 However, the importance of seeking local guidance in applying or adapting ethical
179 guidelines articulated in this Policy must be emphasized.

180 For considerations that apply to research conducted in another country, see [Sections B and C](#)
181 ~~in~~ Chapter 8 ([“Multi-Jurisdictional Research”](#)), [Section B](#).

182 **C. -Applying Provisions of this Policy in Aboriginal Contexts**

183 **The Requirement of Community Engagement in Aboriginal Research**

184 **Article 9.1** Where the research is likely to affect ~~a~~-an [Aboriginal](#) community or
185 communities to which potential participants belong, and where any of the
186 following conditions apply, researchers shall seek engagement with the
187 relevant community:

188 (a) ~~Research~~-[research](#) is conducted on First Nations, Inuit or Métis lands;

189 (b) ~~Recruitment~~[recruitment](#) criteria include Aboriginal identity as a factor for
190 the entire study or for a subgroup in the study;

191 (c) ~~The~~[the](#) research seeks input from participants regarding a community’s
192 cultural heritage, artefacts, Indigenous knowledge or unique
193 characteristics;

194 (d) Aboriginal identity or membership in an Aboriginal community is used as
195 a variable for the purpose of analysis of the research data;

196 | (e) ~~The~~the interpretation of the research results will refer to Aboriginal
197 communities, peoples, language, history or culture.
198 |

199 **Application** While the legal basis for research oversight may vary depending on the
200 community, the practical requirement of engaging community representatives
201 and the ethical obligation to respect community views of welfare remain
202 consistent.

203 Paragraph (a) refers to First Nations, Inuit and Métis lands that include Indian
204 reserves, Métis settlements, lands allocated under an Inuit or First Nations
205 | land claim ~~agreement~~agreements and lands over which a claim has been
206 asserted but not settled, as defined by the Aboriginal community
207 prospectively engaged in research.

208 Paragraph (c) refers to cultural heritage, which includes but is not limited to
209 First Nations, Inuit and Métis peoples’ relations with particular territories,
210 material objects, collective knowledge and skills, and intangibles that are
211 transmitted from one generation to the next – such as folklore, customs,
212 representations or practices. Cultural heritage is a dynamic concept, in that
213 materials, knowledge and practices are continuously adapted to the realities of
214 | current experience. For a further discussion of reference to cultural heritage see,
215 for example, the United Nations *Declaration on the Rights of Indigenous*
216 *Peoples* cited under References at the end of this chapter.

217 Cultural heritage research such as archaeological research and handling of
218 artefacts may raise ethical obligations important to the Aboriginal community
219 that may not be addressed in academic research protocols. Researchers and
220 communities should agree in advance on how to reconcile or address these
221 | divergent perspectives (~~see.~~ (See Article 9.12).

222 Paragraph (c) also refers to Indigenous knowledge. Appropriation of Indigenous
223 knowledge, treatment of such knowledge as a commodity to be traded, or
224 making unauthorized adaptations for commercial purposes may cause offence or
225 | harm to communities from which the knowledge originates. Such ~~violations~~
226 have~~conduct has~~ prompted initiatives in various countries and international
227 agencies to ~~prevent~~address unethical ~~exploitation of, unfair and inequitable~~
228 treatment of Indigenous knowledge and knowledge holders (~~see.~~ (See Article
229 9.18, “Intellectual Property and Copyright”).

230 **Forms of Engagement**

231 Community engagement as defined in this Policy can take varied forms. In geographic and
232 organizational communities that have local governments or formal leadership, engagement

233 would normally take the form of review and approval of a research proposal by a designated
234 body prior to recruiting participants. In less structured situations, (for example, a community
235 of interest), a key consideration for researchers, prospective participants and ~~research ethics~~
236 ~~boards (REBs)~~ is determining the nature and extent of community engagement required. In
237 some situations, the determination may be that the welfare of relevant communities is not
238 affected, and ~~voluntary, informed~~ consent of individuals is sufficient. Communities lacking
239 infrastructure to support community engagement should not be deprived of opportunities to
240 participate in guiding research affecting their welfare (see (See Article 9.14, “~~Strengthening~~
241 ~~Research Capacity~~”).).

242 **Article 9.2** The nature and extent of community engagement in a project shall be
243 determined jointly by the researcher and the relevant community and shall be
244 appropriate to community characteristics and the nature of the research.

245 **Application** First Nations, Inuit and Métis communities differ from one another, and they
246 encompass increasing diversity within their own boundaries as a result of formal
247 education, employment, mobility and intermarriage with non-Aboriginal
248 persons. This diversity makes generalizations about the form of community
249 engagement inappropriate. It also increases the importance of clarifying mutual
250 expectations and obligations with the community and incorporating them in a
251 research agreement.

252 The following list, which is not exhaustive, provides examples to illustrate
253 the forms of Aboriginal engagement that might be appropriate in various
254 types of research.

255 1) Research directly involving a community on First Nation, Inuit or Métis
256 lands with a formal governance structure. For example, a project that
257 examines the incidence of diabetes in Pond Inlet, Nunavut, or the impact
258 ~~on Inuit health~~ of contaminants in animals and plants used for country
259 food on Inuit health.

260 ▪ Permission of the land claims organization that carries authority to
261 approve research in Nunavut is required. Agreement of the hamlet
262 council in Pond Inlet will normally be a condition of approval. The
263 local health committee may co-manage the project.

264 2) Research involving Aboriginal people who comprise a sizeable
265 proportion of the study or community and where Aboriginal-specific
266 conclusions are intended. For example, a comparative study of access to
267 public housing in Prince Albert, Saskatchewan.

268 ▪ First Nations in the district, represented by their tribal council, the
269 local Métis association, urban Aboriginal and women’s organizations
270 may partner with the Prince Albert city council to sponsor, implement
271 and use the results of the housing study.

- 272 | 3) Research focusing on a larger community ~~which~~that is known to include
273 Aboriginal people (regardless of their proportion), and where Aboriginal-
274 specific conclusions are anticipated. For example, a study of student
275 retention in high schools in the Sault Ste. Marie district of Ontario.
- 276 ▪ A committee to advise the District Board of Education and the
277 researchers conducting the retention study may be convened,
278 representing First Nations, Métis organizations and urban Aboriginal
279 people whose children are affected.
- 280 4) Research involving Aboriginal people who comprise a sizeable
281 proportion of the larger community that is the subject of research even if
282 no Aboriginal-specific conclusions will be made. For example, research
283 on employment development programs serving residents of
284 ~~Winnipeg's~~the inner city of Winnipeg in Manitoba.
- 285 ▪ Aboriginal service agencies or political organizations may be engaged
286 to help recruit Aboriginal participants and secure community
287 representation on an oversight committee, to ensure cultural
288 sensitivity in collecting and interpreting data on employment program
289 impacts.
- 290 5) Interviewing a sample of individuals of Aboriginal ancestry across
291 Canada on the impact of a policy in their lives, where the results are not
292 attributable to or likely to affect the community or communities with
293 which they may identify. For example, survey research on the
294 implementation of *Indian Act* provisions requiring ministerial approval of
295 an “Indian’s” will.
- 296 ▪ First Nations, Inuit and Métis individuals, whether or not they identify
297 as members of an Aboriginal community, ~~enjoy~~freedom of
298 expression as does any citizen. They are free to ~~give informed~~consent
299 and to participate in research projects that they consider of personal or
300 social benefit. If the project is unlikely to affect the welfare of the
301 individuals’ communities, local community engagement is not
302 required under this Policy. The necessity or desirability of engaging
303 regional or national representatives of Aboriginal communities in
304 policy research may, however, be determined by other considerations.
- 305 6) Natural sciences research on First Nation~~or~~, Inuit or Métis lands and
306 treaty and land claims agreement areas where Aboriginal people may act
307 as co-investigators or benefit from findings. For example, research
308 focusing exclusively on contaminants in animals or plants in Nunavik that
309 does not make inferences regarding food intake.
- 310 ▪ Research that involves the collection and analysis of tissue samples
311 from animals or plants and not involving human research participants

312 is not covered within the scope of this Policy and does not require
313 REB review. However, funding program guidelines and licensing
314 requirements in the North may impose obligations to engage
315 communities. Community laws, customs or codes of research practice
316 may require securing regional and local permission and reporting
317 findings to communities on whose traditional lands the research takes
318 place. (See NSERC literature on Northern Research Program for
319 professors and students/fellows and Article 9.8 below~~→~~).

320 7) Research that incidentally involves a small proportion of Aboriginal
321 individuals but is not intended to single out or describe characteristics of
322 Aboriginal people in the study. For example, a study of the effectiveness
323 of therapies to control high blood pressure in a sample of hospital
324 outpatients not designed to collect Aboriginal-specific data.

325 ▪ Since Aboriginal participation is incidental rather than scheduled,
326 community engagement is not required. If Aboriginal individuals self-
327 identify during the collection of primary data, researchers should
328 inquire whether culturally appropriate assistance is desired to interpret
329 or support compliance with study protocols. However, it should be
330 noted that including markers of Aboriginal identity in data collection
331 may reveal anomalies that warrant further, more targeted research,
332 which would require community engagement.

333 8) Research exclusively based on publicly available information as defined
334 by this policy. For example, historical, genealogical or analytical research
335 based exclusively on publicly available records or data in accordance
336 with [statutes, legislation](#).

337 ▪ Such research does not involve the collection of data from
338 communities directly or from living persons and is not subject to REB
339 review~~(see (See Article 2.2 in Chapter 2 [“Scope and Approach”])~~.
340 Community engagement is not required. However, findings of such
341 research nevertheless may have an impact on the identity or heritage
342 of persons or communities. Researchers should seek culturally
343 informed advice before use of such data to determine if harms may
344 result and if benefit-sharing should be explored with the original
345 source community. (See Article 9.15).

346 **Respect for ~~Jurisdiction on~~ First Nation, Inuit and Métis ~~Lands~~ [Governing Authorities](#)**

347 **Article 9.3** Where a proposed research project is to be conducted on lands under the
348 jurisdiction of a First Nation government, an Inuit land claim organization or a
349 Métis government, or on traditional lands subject to a claim as defined by the
350 community, researchers shall seek the engagement of formal leaders of the
351 community, except as provided under Articles 9.5, 9.6 and 9.7.

352 **Application** Formal leaders with governance responsibilities on First Nations, Inuit or Métis
353 lands are charged with protecting the welfare of the community. They may
354 approve research or delegate responsibility for reviewing proposals to a local or
355 regional body. Article 8.4 in Chapter 8 (“Multi-Jurisdictional Research”),³
356 applies in such cases, requiring ethics review of research proposals by both by
357 “(i) the ~~research ethics board (REB)~~ at the ~~researcher’s~~ Canadian institution
358 ~~under the auspices of which the research is being conducted~~ and “by(ii) the REB
359 or other responsible ~~review~~ body, ~~where such exists, [or bodies, if any,~~ at the
360 ~~collaborating institutions(s)] in the~~ host research site.” Ethics review by the
361 institutional REB and the responsible community body are required in advance
362 of recruiting and securing consent of individuals.

363 Research involving multiple geographic communities raises complex issues of
364 review and approval. Regional bodies or national organizations may facilitate
365 ethics review and make recommendations but the decision on participation
366 normally rests with the local community.

367 **Engagement with Organizations and Communities of Interest**

368 **Article 9.4** Aboriginal organizations, including First Nations, Inuit and Métis representative
369 bodies, service organizations and communities of interest shall be recognized as
370 communities for the purposes of collaboration in research undertakings and
371 representation of their members in ethical review and oversight of projects.

372 **Application** Research affecting First Nations, Inuit and Métis peoples is often initiated
373 outside the Aboriginal community and carried out by non-Aboriginal
374 personnel. Researchers have often neglected to inform participants and
375 communities of results and they have afforded Aboriginal people little
376 opportunity to correct misinformation or to challenge ethnocentric
377 interpretations. In light of such experience, many Aboriginal people feel
378 apprehensive about the activities of researchers and they are reluctant to
379 participate in research.

380 A majority of persons who self-identify as Aboriginal live in rural and urban
381 communities outside of designated Aboriginal lands. Issues affecting their
382 welfare are under-researched. Political organizations, Friendship Centres,
383 housing associations, healing circles and many other groups that have come
384 together are potential partners in creating knowledge to enhance the welfare
385 of their own communities and society at large.

386 **Complex Authority Structures**

387 **Article 9.5** Where alternatives to securing the agreement of formal leadership are proposed
388 for research on First Nations, Inuit or Métis lands or in organizational
389 communities, researchers should engage community processes and document
390 measures taken, to enable the ~~research ethics boards (REBs)~~ to review the

391 proposal with due consideration of complex community authority structures.

392 | **Application** ~~Research ethics boards~~REBs should not assume that approval of a project by
393 formal leaders is the only avenue for endorsing a project. In some communities
394 and some domains of knowledge, authority to permit and monitor research rests
395 with knowledge keepers designated by custom rather than election or
396 appointment. In First Nations settings, a confederacy council spanning several
397 communities may be recognized as having authority over its members’
398 traditional knowledge. In an Inuit community, the hamlet council, an Elders’
399 | circle and a ~~Hunters~~Hunters’ and ~~Trappers~~Trappers’ society may have
400 overlapping responsibility and expertise with respect to the knowledge being
401 sought. Métis Elders dedicated to conserving Michif language may assert their
402 autonomy from political leaders but choose to collaborate with educational or
403 cultural agencies.

404 The preferred course is to secure approval for research from both formal leaders
405 of a community and customary authority. This is especially important for
406 outsiders to communities, whose presence or intentions might be challenged.
407 Researchers should engage community processes, including the guidance of
408 moral authorities such as Elders, to avert potential conflict. These measures
409 should be documented to assist the REB in considering the community
410 engagement processes proposed ~~(see. (See Article 9.10, “Requirement to Advise~~
411 ~~REB on Plan for Community Engagement”)~~.

412 **Recognizing Diverse Interests Within Communities**

413 **Article 9.6** In engaging communities, researchers should ensure, to the extent possible,
414 that they take into consideration the views of all relevant sectors, including
415 communities of interest who may not have a voice in the formal leadership of
416 a geographical or organizational community. Vulnerable groups or
417 individuals may need or desire special measures to ensure their safety or
418 inclusion.

419 **Application** Vulnerable or marginalized subgroups within communities should be not be
420 deprived of opportunities to participate in guiding research affecting their
421 welfare. Covert research or direct challenges to legitimate authority risk
422 increasing participants’ vulnerability, deepening rifts within the community and
423 actually impeding the advancement of social justice. Strategies that have proven
424 effective to accommodate diversity include: advocacy by moral authorities in
425 the community; special measures to protect the identity of participants in small
426 communities; identifying research questions that include rather than divide
427 interest groups; or expanding the coverage of a project to multiple communities
428 where personal interests are less prominent. In some cases, the risks to
429 participants and communities involved with or affected by the proposed research
430 | outweigh the potential benefits likely to be gained and the research should not
431 be undertaken.

432 **Critical Inquiry**

433 **Article 9.7** Research that critically examines the conduct of public institutions or persons in
434 authority may do so ethically, notwithstanding the usual requirement, in
435 research involving Aboriginal peoples, of engaging representative leaders.

436 **Application** Considerations in conducting critical inquiry are discussed more fully in
437 | Article 3.6 of Chapter 3 (“Free and Informed Consent”). As in the case of
438 | research involving vulnerable subgroups within an Aboriginal community
439 | (see Article 9.6), critical inquiry will require creative approaches to ensure
440 that cultural norms are respected, that the safety of participants is protected
441 and that the welfare of the larger community is not disrupted.

442 For example, the Sisters in Spirit project of the Native Women’s Association
443 of Canada (NWAC) launched in 2005 for a five-year period illustrates
444 research of national scope that incorporates a critical dimension. The project
445 involves interviewing families of missing and murdered Aboriginal women in
446 urban and rural settings, on and off First Nations territory. It examines,
447 among other matters, the adequacy of public institutions and services,
448 Aboriginal and non-Aboriginal, to protect the women’s well-being and
449 support families in their efforts to deal with their losses. The objective is to
450 effect policy change and improve the safety and well-being of Aboriginal
451 women in Canada. NWAC has published its commitment to participatory
452 | research and the principles and practices that protect [the](#) privacy and well-
453 being of participants. The project builds on NWAC’s established moral
454 authority to investigate sensitive matters, welcomes endorsement by a
455 national political organization, engages the cooperation of regional health
456 directors where available, and informs local authorities of the presence of its
457 researchers on First Nations territory.

458 **Respect for Community Customs and Codes of Practice**

459 **Article 9.8** Researchers have an obligation to become informed about and to respect the
460 relevant customs and codes of research practice that apply in the particular
461 community or communities affected by their research. Inconsistencies between
462 community custom and this Policy should be identified and addressed, where
463 possible, in advance of initiating the research.

464 **Application** First Nations, Inuit and Métis codes of research practice derive from laws and
465 customs of predominantly oral cultures. While some rules may be in written
466 form, their interpretation is dependent on experiential knowledge acquired
467 through interactions in the community. An example is the strict limitation on
468 | making publicly available sacred knowledge ~~which~~ [that](#) might be revealed
469 within a trusting relationship. In academic culture, rules regarding limits on
470 disclosure of information would reasonably be incorporated in a research
471 protocol.

472 In Aboriginal communities, custom may restrict the observation, recording or
473 reporting of ceremonies or certain performances and require approval of
474 appropriate individuals. Article 10.3 addresses research involving observational
475 studies, the requirement for research ethics review and the ethical implications
476 associated with observational research approaches, which may infringe on ~~free~~
477 ~~and informed~~ consent and privacy.

478 Many First Nations communities across Canada have adopted an ethics code
479 originally developed to govern practice in the First Nations Regional Health
480 Survey. It asserts ownership, control, access and possession of research
481 processes affecting participant communities and is generally referred to as
482 OCAP. It addresses issues of privacy, intellectual property, data custody and
483 secondary use of data, which are also covered later in this chapter. Researchers
484 should consult with their own institutions to ensure that ~~compliance with the~~
485 ~~application of~~ OCAP or other community-based ethics codes is consistent with
486 institutional policies, particularly on issues of intellectual property. Where
487 conflicts exist, they should be addressed and resolved prior to the
488 commencement of the research. (See Article 9.18).

489 The ~~obligation~~ ~~ethical duty~~ to respect community laws, customs and
490 responsibilities and to engage the relevant community applies ~~equally~~ to First
491 Nations, Inuit and Métis researchers conducting research in their own local or
492 cultural communities, if they are also members of research institutions adhering
493 to this Policy. First Nations, Inuit and Métis scholars attached to academic
494 institutions as faculty members, students or research associates are increasingly
495 engaged in research involving their own communities and sometimes their own
496 family members. They are generally exempt from restrictions on physical access
497 to territory or personal access to community members.

498 Life history and language research are examples of research areas where insider
499 relationships and skills provide unique opportunities to extend the boundaries of
500 knowledge. While it can be argued that recording the life history of an elderly
501 relative is a family matter rather than a community matter, the potential impact
502 of such research on the wider community, conflicts between the individualist
503 norms of the academic environment and the norms of the community, and the
504 possibility of unclear or mistaken assumptions on the part of participant and
505 researcher make community engagement important. The relevant community to
506 be engaged in such cases might be extended family members, peers of the
507 participant with whom the researcher's interpretations can be validated, or
508 Elders knowledgeable about cultural rules governing disclosure of privileged
509 information.

510 **Institutional Ethics Review Required**

511 | **Article 9.9** Ethics review by community ~~research ethics boards (REBs)~~ or other responsible
512 bodies at the research site will not be a substitute for review by institutional

513 REBs and will not exempt researchers affiliated with an institution from seeking
514 REB approval at their institution, subject to Article 8.1.

515 **Application** Applying this Policy in a way that accommodates the diversity of First Nations,
516 Inuit and Métis cultures and communities is complex. For example, the fit
517 between institutional policies and community laws, customs and codes of
518 research practice may be unclear, requiring researchers to adapt conventional
519 practice or negotiate a resolution.

520 The presumption that community engagement is required in research involving
521 Aboriginal participants is consistent with Article 8.43, which provides that
522 research conducted outside the jurisdiction of the researcher’s institution “shall
523 undergo prospective ethics review both by “(i) the REB at the Canadian
524 institution under the auspices of which the research is being conducted and
525 by(ii) the REB or similar other responsible review body, ~~where such exists, [or~~
526 bodies, if any, at the ~~collaborating institutions(s)] in the~~ host research site.””.

527 Article 8.1 permits review models for multi-site research that do not require
528 separate ethics review by each site involved in a research project. In cases where
529 the community is the direct recipient of funding and has constituted a local REB
530 that is party to such an agreement with the researcher’s institution, review by the
531 institution’s REB may not be required. (See Article 8.1 ~~in Chapter 8, [“Multi-~~
532 Jurisdictional Research”].).

533 In accordance with Article 8.4, communication between the institutional REB
534 and the responsible agency in the community may assist in resolving
535 inconsistencies between institutional policy and community laws, customs and
536 codes of research practice. If a community ethics review is required in addition
537 to the mandatory institutional REB review, reconciling differences may require
538 re-submission to one or the other review body.

539 Researchers and REBs should recognize that ethics review by community
540 bodies will often pursue purposes and apply criteria that differ from the
541 provisions of this Policy. The express purpose of most Aboriginal community
542 codes of research practice is to ensure relevance of research undertakings to
543 community needs and priorities and respect for First Nations, Inuit and Métis
544 identities, cultures and knowledge systems. While community codes of practice
545 and research agreements typically share many of the goals of institutional
546 policies, the approaches to achieving those goals may differ significantly. It is
547 therefore inappropriate to insist on uniformity between community practices and
548 institutional policies. For example, when researchers seek to interview Elders
549 willing to share their knowledge according to traditional customs of consent,
550 REBs should not impose language and processes that may be experienced as
551 culturally inappropriate or awkward.

552 In cases where review of research on topics related to Aboriginal peoples is
553 regularly required, the REB membership should be modified to ensure that
554 relevant and competent knowledge and expertise in Aboriginal cultures are
555 captured within its regular complement. For occasional review of Aboriginal
556 research appointment of ad hoc advisors or delegation to a specialized or
557 multi-institutional REB may be appropriate. (~~See Articles 6.4, 6.5 in Chapter~~
558 ~~6 [“Governance of Research Ethics”] and Article 8.1 in Chapter 8 [“Multi-~~
559 ~~Jurisdictional Research”].).~~

560 The membership of community review bodies of First Nations, Inuit or Métis
561 communities will not necessarily duplicate the membership criteria set out in
562 this Policy. In the context of scarce resources in community organizations, the
563 same personnel may be involved in reviewing the ethics of a proposal and co-
564 managing the research. An expectation that conflict of ~~interest~~ interests will be
565 managed by separating ethics review and project management functions may
566 impose unsupportable demands on small communities. Researchers and
567 participating Aboriginal communities should address how in those
568 circumstances ethical safeguards of the community and its members are best
569 achieved when multiple roles are assumed by the same person. (See Chapter 7
570 [~~“Conflict of Interests”~~]).

571 **Requirement to Advise the ~~Research Ethics Board~~ REB on a Plan for Community**
572 **Engagement**

573 **Article 9.10** When proposing research expected to involve First Nations, Inuit or Métis
574 participants, researchers shall advise their ~~research ethics board~~ (REB) how they
575 have engaged or intend to engage the relevant community or, alternatively,
576 present a rationale as to why an exception to the requirement is appropriate.

577 **Application** In order for REBs to consider whether the form of community engagement is
578 appropriate, they will require evidence in the form of (a) a preliminary or formal
579 research agreement between the researchers and the responsible body in the
580 research site; (b) documentation of a written or oral decision to approve the
581 proposed research in a group setting; (c) a written summary of advice received
582 from a culturally informed advisory group or ad hoc committee, for example in
583 an urban community of interest. Provision of a research agreement is
584 particularly emphasized in health research funded by CIHR (~~see~~. (See CIHR
585 *Guidelines for Health Research Involving Aboriginal People* in the Reference
586 section at end of this chapter).

587 Where a researcher has an ongoing relationship with a community, a letter
588 from formal or customary leaders in the relevant community may signal
589 approval to proceed with the research.

590 Although researchers must offer the option of engagement, a community may
591 choose to engage nominally or not at all, despite being willing to allow the

592 research to proceed. A community may, for example, support a study carried
593 out independent of community influence in order to use scientifically
594 defensible results to validate a negotiating position. In instances where
595 community engagement is not taken up, researchers must present to the REB
596 the steps they took to invite and facilitate engagement by the community.
597 Lack of engagement by communities may also be due to inadequate financial
598 or human resources. Researchers should demonstrate what efforts they have
599 made to assist in capacity-building to facilitate engagement.

600 **Research Agreements**

601 **Article 9.11** Where a community has formally engaged with a researcher or research team
602 through a designated representative, the terms and undertakings of both the
603 researcher and the community should be set out in a research agreement before
604 participants are recruited.

605 **Application** Research agreements serve as a primary means of clarifying and confirming
606 mutual expectations and, where appropriate, commitments between researchers
607 and communities. The scope of the agreement will depend on the level of
608 engagement which the community desires, and the availability of resources to
609 support community participation.

610 At a minimum, the agreement should address the ethical protections that would
611 apply in securing individual consent for a comparable project and should specify
612 any commitments regarding collective community participation and decision-
613 making, sharing of benefits and review and updating of the agreement.
614 Expanding on information normally provided to an individual participant (see
615 Article 3.2), agreements typically set out the purpose of the research and detail
616 mutual responsibilities in project design, data collection and management,
617 analysis and interpretation, production of reports and dissemination of results.

618 Where a community has adopted or adheres to a code of research practice,
619 the agreement may set out detailed responsibilities. In less formal
620 circumstances, the agreement may be relatively brief and subject to
621 clarification as the project unfolds. *CIHR Guidelines for Health Research
622 Involving Aboriginal People* (2007) provide examples of elements that may
623 be included in research agreements (see [See](#) Reference section at the end of
624 this chapter).

625 Research agreements are increasingly being recognized by academic
626 institutions and the researchers associated with them as providing reference
627 points for ethics review and approval on such elements as consent,
628 confidentiality and intellectual property. Agreements that specify procedures
629 for community ethics review, included as part of the institutional ethics
630 application, can provide contextual information and guidance for REBs
631 conducting initial review of applications and continuing ethics review

632 throughout the project. Researchers should check with their institutions
633 regarding signing authority for research agreements that include undertakings
634 beyond those normally included in a consent form.

635 Community agreement that a research project may proceed is not a substitute
636 for securing the free and informed consent of individuals being recruited to
637 participate in that project, in accordance with Chapter 3 (“Free and Informed
638 Consent”).

639 Building relationships, clarifying the goals of a project and negotiating
640 agreements requires substantial investment of time and resources on the part
641 of the community and researcher. Development and participation costs
642 incurred by the community and the researcher should be factored into
643 proposals to the extent possible within funding guidelines.

644 Collaborative Research

645 **Article 9.12** While community engagement is appropriate in any research that affects
646 Aboriginal communities, researchers should consider applying a
647 collaborative or participatory approach as appropriate to the nature of the
648 research and the level of engagement desired by the community.

649 **Application** This Policy encourages collaborative research with First Nations, Inuit and
650 Métis communities as a means of facilitating mutually respectful and
651 productive relations.

652 Collaborative research is generally understood to involve respectful
653 relationships among colleagues, each bringing distinct expertise to a project.
654 Collaboration often involves one or other of the partners taking primary
655 responsibility for certain aspects of the research, such as addressing sensitive
656 issues in community relations or scientific analysis and interpretation of data.

657 Community-based research is research that takes place at community sites and
658 involves collaboration between community agencies and scientific researchers.
659 It often seeks to address a research topic of practical relevance to the
660 community. The terms “community-based research” and “participatory
661 research” are often used interchangeably or in combination.

662 Participatory research is a method that promotes research relevant to local
663 concerns, action and social change, increased community skills, capacity
664 building, sustainability, and knowledge translation. In its fullest expression,
665 participatory research engages researchers and community members in an active
666 partnership that shares decision-making throughout the research process: —
667 identifying the issue to be researched, developing the research design,
668 collecting, analyzing, and interpreting the data, developing conclusions and
669 disseminating results.

670 An outcome of collaborative research highly valued by communities is
671 increased capacity to carry out autonomous research that can more readily be
672 conducted in Aboriginal languages and oral modes. The exploration,
673 articulation and application of Indigenous knowledge in the local community
674 is thus advanced, potentially benefiting other communities through
675 knowledge transfer.

676 **Mutual Benefits in Collaborative Research**

677 **Article 9.13** Collaborative research should be relevant to community needs and priorities
678 and should benefit the participating community as well as extend the
679 boundaries of societal knowledge.

680 **Application** To benefit the participating community a research project should be relevant
681 and have the potential to produce valued outcomes from the perspective of
682 the community and its members.

683 Relevance and community benefit can take a number of forms depending on
684 the type of research being conducted. For example, genetic research on
685 diabetes in a First Nations community is unlikely to benefit the community in
686 the short term, but collaboration may facilitate increased knowledge of the
687 condition and change that improves health outcomes. Collaborative research
688 can thus accommodate basic as well as applied research, short-term and long-
689 term benefits. In another example, a study of housing and homelessness in an
690 Inuit community was initiated at the request of the community. Using
691 participatory research methods and social science tools, the nature, extent and
692 consequences of the local housing shortage was documented, enabling the
693 community to communicate its needs effectively to non-Inuit (Qallunaat)
694 authorities. Training workshops provided employment and transferred skills
695 to Inuit youth involved in data collection. The project provided field
696 experience in community-based research for university student assistants and
697 materials useful to other Inuit communities in subsequent research.

698 Communities participating in research place a high priority on access to
699 research data that will allow them to address pressing issues through
700 community-generated policies, programs and services. They also seek to
701 share in the benefits of research activities in the form of direct research
702 grants, release time for project personnel, overhead levies on shared projects
703 and commercialization of research discoveries.

704 **Strengthening Research Capacity**

705 **Article 9.14** Research projects should support the enhancement of the skills of community
706 personnel in research methods, project management and ethical review and
707 oversight.

708 **Application** To the degree possible, researchers should foster education and training of
709 community members to enhance their participation in research projects.
710 Employing Aboriginal research assistants and translators is already common
711 practice in community-based projects. Extending skills transfer through a
712 rational program of training will support collaboration with institutions and
713 advance the capacity of communities to initiate and implement their own
714 research.

715 Communities vary widely in the level of human and material resources they
716 have available to collaborate with research initiatives. Small, remote
717 communities and many urban communities of interest have limited
718 organizational resources to advise or collaborate in research. The least
719 organizationally developed communities are the most vulnerable to
720 exploitation. Researchers, [research ethics boards \(REBs\)](#) and communities
721 leaders should strive to protect the interests of such communities by
722 undertaking research and supporting the enhancement of capacity to
723 participate in research.

724 Funding programs that target the development of Aboriginal research and
725 capacity building seek to generate significant research training opportunities
726 for Aboriginal students, allowing researchers to include in their grant
727 applications stipends for undergraduate, master’s degree or doctoral students
728 or post-doctoral researchers, as appropriate, with priority given to Aboriginal
729 people.

730 **Recognition of the Role of Elders**

731 **Article 9.15** Researchers should engage the community in determining appropriate
732 recognition for the unique advisory role of Elders in the design and execution
733 of research and interpretation of findings in the context of cultural norms and
734 traditional knowledge.

735 **Application** Recognition of Elders may include adherence to customary prescribed
736 procedures to solicit their involvement – feasting, gift-giving, providing
737 honoraria, acknowledging contributions by name or, as directed, withholding
738 the Elder’s identity in reports and publications. Elders are now being
739 recognized in research proposals and grant applications as providing access
740 to community networks, ethical guidance to researchers, and advice in
741 interpreting findings in the context of traditional knowledge.

742 **Privacy and Confidentiality**

743 **Article 9.16** Where research agreements provide that community partners will have
744 limited or full access to identifiable personal data, the consent of participants
745 to such disclosure shall form part of the individual consent [procedure process](#).

746 **Application** Researchers and community partners should consider early in the design of
747 the research how community codes of research practice fit with provisions for
748 privacy and confidentiality set out in Chapter 5 (“[Privacy and](#)
749 [Confidentiality](#)”). Where conflicts exist, they should be resolved in advance
750 of starting the research.

751 In some First Nations communities, privacy and confidentiality of
752 identifiable personal and community information may be affected by
753 application of the principles of ownership, control, access and possession
754 (OCAP) ~~(see)~~. (See definition under Article 9.8). The Regional Health
755 Survey administered by regional First Nations organizations has addressed
756 balancing confidentiality and access by having communities designate a
757 regional organization to hold data while local authorities make decisions on
758 who can access the data and under what conditions. In practice, the
759 organization that serves as data steward evaluates requests for information,
760 and its recommendations to community authorities have considerable
761 influence.

762 Small Aboriginal communities are characterized by dense networks of
763 relationships, with the result that de-identifying individual data is often not
764 sufficient to mask identities, even when data are aggregated. Communities
765 themselves have distinguishing characteristics, which in some cases have
766 compromised efforts to disguise the site of research and led to the
767 stigmatization of whole communities. Some Aboriginal research participants
768 are reluctant to speak to interviewers from their own community because of
769 privacy concerns.

770 On the other hand, in some social sciences and humanities research, the
771 significance of information is tied to the identity of the source, and individual
772 attribution, with consent, is appropriate. Communities partnering in research
773 may wish to be acknowledged for their contribution.

774 Privacy protections in research are evolving. Respect for and accommodation
775 of First Nations, Métis and Inuit priorities on joint ownership of the products
776 of research and maintaining access to data for community use should guide
777 research practices, with appropriate deference to federal, provincial and
778 territorial legislation on privacy.

779 **Interpretation and Dissemination of Research Results**

780 **Article 9.17** Researchers should afford community representatives engaged in
781 collaborative research an opportunity to react and respond to research
782 findings before the completion of the final report, in the final report, and in
783 all relevant publications resulting from the research.

784 **Application** Communities consider that their review and approval of reports and academic
785 publications is essential to validate findings, protect against misinterpretation,
786 and maintain respect for Indigenous knowledge, which may entail limitations
787 on its disclosure. If disagreement about interpretation arises between
788 researchers and the community and cannot be resolved, researchers should
789 afford the group an opportunity to make its views known, or they should
790 accurately report any disagreement about the interpretation of the data in their
791 reports or publications.

792 Final reports shall be made available to the community participating in the
793 research. Researchers and communities should clarify the extent to which
794 research findings will require translation, plain language summaries or oral
795 presentations in order to make the research findings accessible to the
796 community.

797 An Aboriginal community and those who participated in the research should
798 have the option to decide how collective or individual contributions to the
799 research project will be acknowledged and credited in the dissemination of
800 results, for example at conferences and seminars.

801 **Intellectual Property ~~and Copyright~~**

802 **Article 9.18** In collaborative research, intellectual property rights ~~and including~~ copyright
803 should be discussed by researchers, communities and institutions ~~in advance~~
804 ~~and~~ and the assignment of rights [or the grant of licences and interests in](#)
805 [copyrighted material that may flow from the research](#) should be specified in
806 [advance of the research in](#) a research agreement, as appropriate.

807 **Application** There is an ongoing international debate regarding misappropriation,
808 commodification, and unfair or harmful commercial exploitation of
809 Indigenous knowledge.

810 First Nation, Inuit and Métis laws and customs distinguish ~~between~~among
811 knowledge that can be publicly disclosed, disclosed to a specific audience or
812 disclosed under certain conditions. [Determination of what information may](#)
813 [be shared and with whom will depend on the culture of the Aboriginal](#)
814 [community in question. Any restrictions on access to or use of traditional or](#)
815 [sacred knowledge shared in the course of the research project should be](#)
816 [addressed in the research agreement.](#)

817 Researchers, institutions and communities may need to adopt a two-tiered
818 approach: first to address issues regarding access to data and use or
819 publication of findings; and second, to address issues related to commercial
820 applications of the results from collaborative research. [They should agree on](#)
821 [what a researcher/student can use for publication. They should negotiate](#)

822 ~~separately all intellectual property and copyright issues linked to commercial~~
823 ~~outcomes (if any) from the research.~~

824 ~~The products~~Regarding the first issue (access and use of collaborative
825 ~~research should be regarded as the intellectual property of both the researcher~~
826 ~~and the participating individuals or community, whichever is appropriate.~~
827 ~~The terms on which intellectual property and copyright are shared should be~~
828 ~~specified in data) a research agreement ~~and~~ may ~~include~~ set out any limits to
829 ~~on~~ the disclosure of personal or privileged information, (subject to applicable
830 legal and regulatory requirements and the discussion in Chapter 5 of this
831 Policy). It might include a right to review reports and publications, attribution
832 of authorship, intellectual property protection and retention of copyright.
833 Arrangements for regarding the research prior to publication or limits on the
834 release of, or access to research results can include open or restricted
835 dissemination, joint ownership or assignment of ownership-, subject to
836 applicable laws. The agreement may also set out any interests, licences or
837 assignments in copyright flowing from publications about or based on the
838 research.~~

839 With respect to commercialization of results, the use, assignment or licensing
840 of any intellectual property, such as patents or copyright, resulting from the
841 research (if any) may also be addressed in an agreement.

842 Researchers should consult the research office of their institution before
843 entering into a research agreement that includes ~~copyright and~~ intellectual
844 property provisions. Researchers should consult the program literature or
845 policies on intellectual property and copyright adopted by the federal
846 research agencies NSERC, SSHRC and CIHR available on their websites and
847 seek legal advice where appropriate.

848 It is widely recognized that some Indigenous knowledge may have
849 commercial applications and lead to the development of marketable products,
850 for example, traditional plant medicines. If the proposed research has explicit
851 commercial objectives or direct or indirect links to the commercial sector,
852 these should be clearly communicated to all parties as a requirement of free
853 and informed consent.

854 ~~The researcher and the community should openly discuss potential secondary~~
855 ~~use of traditional and sacred knowledge, and the research agreement should~~
856 ~~address how best to protect this knowledge.~~

857 **Prospective Collection of Human Biological Material Involving Aboriginal Peoples**

858 **Article 9.19** As part of community engagement, researchers shall address and specify in
859 the research agreement, ~~where such exists,~~ the rights and proprietary interests
860 of individuals and communities, to the extent such exist, in human biological

861 materials and data to be collected, stored and used in the course of the
862 research.

863 **Application** Canadian law does not provide clear recognition of property rights in human
864 biological materials. Researchers should be aware, however, that Aboriginal
865 people and communities express proprietary interests in data and biological
866 samples collected for research. Consistent with Chapter 12, and Article 9.11
867 of this ~~policy~~ Policy, researchers and communities should address and specify
868 in the research agreement-;

- 869 ▪ the objectives for collection, use and storage of human biological
870 materials ~~as well as~~;
- 871 ▪ the roles and responsibilities regarding custodianship of the data and the
872 samples-; and
- 873 ▪ any future use of these samples and associated data, including material
874 transfer agreements to third parties and any subsequent requirements for
875 community engagement.

876 Individuals who are invited to donate biological materials shall give their free
877 and informed consent in accordance with Articles 12.1 and 12.2.

878 **Consent and Secondary Use of Data or Human Biological Materials Originating from** 879 **Aboriginal Peoples**

880 **Article 9.20** Secondary use of data that is identifiable as originating from a specific
881 community, or a segment of the Aboriginal community at large, requires
882 research ethics board (REB) review and may warrant re-consent from
883 individuals, new or renewed agreement of communities, or seeking culturally
884 informed advice about protection of cultural heritage or representations of
885 Indigenous knowledge or society.

886 **Application** Misrepresentation of Aboriginal peoples, unauthorized use of data or
887 tissues human biological materials without appropriate engagement with the
888 source community or consent of participants, and lack of reporting to
889 communities on research outcomes have created ongoing sensitivity about
890 secondary use of data collected for approved purposes. For example,
891 members of Nuuchahnulth communities in British Columbia provided
892 blood samples for research on rheumatic disease. They vigorously protested
893 use of the blood components for subsequent unauthorized genetic research. In
894 addition, there are fears in First Nation communities that access to health data
895 for purposes other than treatment will facilitate unauthorized government
896 surveillance.

897 The privacy of individual participants in research is normally protected by
898 removing information that would identify them personally. De-identified data
899 are added to a data pool and are available for analysis and sometimes for

900 secondary use. Consistent with the general provisions set out in Chapter 5
901 (~~“Privacy and Confidentiality”~~), secondary use of data collected initially for
902 other purposes, from which personal identifiers have been removed, does not
903 require REB review.

904 As discussed in Chapter 5, access to data containing identifiable personal
905 information may be needed for some types of research. For example,
906 longitudinal studies require access to identifiable information contained in
907 data banks, although consent for additional studies was not obtained from
908 original informants and it may be impracticable to obtain it subsequently.
909 Such secondary usage requires REB review (see Articles 5.5 to 5.7 ~~in~~
910 ~~Chapter 5 [“Privacy and Confidentiality”]~~), and the REB may allow ~~an~~
911 ~~alteration or~~ waiver of consent under certain conditions ~~(see Article 3.8. (See~~
912 ~~Section B, in Chapter 3 [“Free and Informed Consent”])~~).

913 Secondary use of data identifiable as originating from Aboriginal participants
914 or communities shall be subject to REB review to avoid harms ensuing from
915 inadvertent identification of communities, potential misuse of cultural
916 heritage, or misrepresentation of Indigenous knowledge when interpretation
917 of data is no longer guided by community engagement. Any constraints
918 imposed on use of the data in the original project should be noted if such
919 information is available. Consistent with Article 5.6, the researcher should
920 propose to the REB an appropriate strategy for securing agreement of the
921 relevant individuals or group, or, if this is impossible or impracticable, there
922 should be consultation with one or more organizations that are likely to
923 represent the views and interests of the original participants.

924 A common example of ~~unauthorized~~ secondary use of data that are
925 identifiable as originating from a specific community without appropriate
926 engagement with the community is the practice of accessing traditional plant
927 knowledge from the published literature to inform commercial development
928 of products. In fields such as ethnobotany there is a significant amount of
929 traditional knowledge that was published without the awareness or consent of
930 the original knowledge holders. Researchers should seek culturally informed
931 advice before use of such data to determine if harms may result and if
932 benefit-sharing should be explored with the original source community.

933 **Article 9.21** Researchers who propose research involving secondary use of human
934 biological materials originating from Aboriginal peoples shall:

935 (a) obtain ~~research ethics board (REB)~~ approval for the proposed research;
936 and

937 (b) engage the community from which the biological materials originated in
938 accordance with any existing research agreement or the REB’s direction;
939 and

- 940 (c) obtain consent of individuals from whom the biological materials
941 originated unless:
- 942 (i) an existing research agreement permits secondary use based on
943 individual consent given at the time biological materials were
944 initially collected; or
- 945 (ii) the REB and the community agree that individual consent may be
946 waived in accordance with Articles 12.53 or 12.6.4.

947 **Application** Where the researcher can satisfy the REB that secondary use is consistent
948 with an existing research agreement, the REB may require that the researcher
949 engage the community from which the biological materials and associated
950 identifiable information originate in accordance with the terms of the
951 research agreement. New individual consent to secondary use is not required
952 where the original consent authorized future use. Where secondary use has
953 not been specified in the research agreement and authorized by the original
954 individual consent, researchers shall engage the community from which the
955 biological materials and identifiable information originate prior to initiating
956 secondary use. Individual consent for the secondary use is required unless the
957 REB and the community agree that ~~Articles~~either Article 12.43 or 12.54
958 applies.

959 | **Endnotes**

ⁱ [Constitution Act, 1982, s. 35; www.laws.justice.gc.ca/en/const/9.html#anchors:7-bo-ga:l II](http://www.laws.justice.gc.ca/en/const/9.html#anchors:7-bo-ga:l II)

ⁱⁱ [See Chapter 1, regarding the scope of definitions used in this Policy.](#)

ⁱⁱⁱ [Constitution Act, 1982, s. 35; www.laws.justice.gc.ca/en/const/9.html#anchors:7-bo-ga:l II](http://www.laws.justice.gc.ca/en/const/9.html#anchors:7-bo-ga:l II)

References

- [Aboriginal Research Ethics Initiative of the Interagency Advisory Panel on Research Ethics, “Issues and Options for Revisions to the TCPS: Section 6: Research Involving Aboriginal Peoples,” February 2008, www.pre.ethics.gc.ca/eng/policy-politique/initiatives/reports-rapports/riap-rapa/](http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/reports-rapports/riap-rapa/)
- [Canadian Institutes of Health Research, CIHR Guidelines for Health Research Involving Aboriginal People, May 2007, www.cihr-irsc.gc.ca/e/29134.html](http://www.cihr-irsc.gc.ca/e/29134.html)
- [———, Best Practices for Protecting Privacy in Health Research, September 2005, www.cihr-irsc.gc.ca/e/29072.html](http://www.cihr-irsc.gc.ca/e/29072.html)
- [First Nations Regional Longitudinal Health Survey \(RHS\).](#)

www.rhs-ers.ca/english/

- [First Nations Centre. 2007. *OCAP: Ownership, Control, Access and Possession*. Sanctioned by the First Nations Information Governance Committee, Assembly of First Nations. Ottawa: National Aboriginal Health Organization, \[www.naho.ca/english/pub_research.php\]\(http://www.naho.ca/english/pub_research.php\)](#)
- [ITK and NRI. 2007. *Negotiating Research Relationships with Inuit Communities: A Guide for Researchers*. Scot Nickels, Jamal Shirley, and Gita Laidler \(eds\). Inuit Tapiriit Kanatami and Nunavut Research Institute: Ottawa and Iqaluit, 38 pp. \[www.itk.ca/publications/negotiating-research-relationships-inuit-communities-guide-researchers\]\(http://www.itk.ca/publications/negotiating-research-relationships-inuit-communities-guide-researchers\)](#)
- [NAHO Ajunnginiq Centre. *Research and Research Ethics Fact Sheets*, \[www.naho.ca/inuit/e/ethics/\]\(http://www.naho.ca/inuit/e/ethics/\)](#)
- [Royal Commission on Aboriginal People. *Report of the Royal Commission on Aboriginal Peoples \(1996\)*. “Ethical Guidelines for Research” in *Volume 5, Renewal: A Twenty-Year Commitment*. Canada Communications Group, pp. 325-8. \[www.ainc-inac.gc.ca/ap/rrc-eng.asp\]\(http://www.ainc-inac.gc.ca/ap/rrc-eng.asp\)](#)
- [United Nations Educational, Scientific and Cultural Organization, *Universal Declaration on Bioethics and Human Rights*. Adopted October 19, 2005 by the 334th session of the General Conference of UNESCO. 2005. \[www.portal.unesco.org/shs/en/ev.php-URL_ID=1883&URL_DO=DO_TOPIC&URL_SECTION=201.html\]\(http://www.portal.unesco.org/shs/en/ev.php-URL_ID=1883&URL_DO=DO_TOPIC&URL_SECTION=201.html\)](#)
- [United Nations \(1992\). *Convention of Biological Diversity*. \[www.cbd.int/convention/convention.shtml\]\(http://www.cbd.int/convention/convention.shtml\)](#)
- [United Nations \(2007\). *Declaration on the Rights of Indigenous Peoples*. \[www.un.org/esa/socdev/unpfii/documents/DRIPS_en.pdf\]\(http://www.un.org/esa/socdev/unpfii/documents/DRIPS_en.pdf\)](#)