

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.

Submit your written comments by e-mail at draft2e@pre.ethics.gc.ca, by fax to 613-996-7117 or mail your comments to:

Interagency Secretariat on Research Ethics
350 Albert Street
Ottawa, ON K1A 1H5

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

November 2009

REVISED

CHAPTER 9

Research Involving Aboriginal Peoples in Canada

Comment Period Closing Date: March 1, 2010



Interagency Advisory Panel
on Research Ethics

Groupe consultatif interagences
en éthique de la recherche

Comments on this document can be sent to:

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Draft: Chapter 9

3117

3118 RESEARCH INVOLVING ABORIGINAL PEOPLES IN CANADA

3119 INTRODUCTION

3120 The Aboriginal and treaty rights of Aboriginal peoples, including Indian (First Nations),
3121 Inuit and Métis peoples, which were recognized and affirmed in the *Constitution Act, 1982*,
3122 create an obligation on public institutions to acknowledge and support the desire of First
3123 Nations, Inuit and Métis to maintain their collective identities and the continuity of their
3124 cultures.

3125 This chapter acknowledges the unique status of the Aboriginal peoples of Canada. It
3126 interprets how the value of respect for human dignity and the core principles of respect for
3127 persons, concern for welfare, and justice, as articulated in Chapter 1 (“Ethics Framework”)
3128 apply to research involving Aboriginal peoples. It accords respect to Indigenous knowledge
3129 systems by ensuring that distinct world views are represented wherever possible in planning
3130 and decision-making, from the earliest stages of conception and design of projects through
3131 to analysis and dissemination of results. It affirms Aboriginal rights, interests and
3132 responsibilities as reflected in community customs and codes of research practice in order to
3133 better ensure balance in the relationship between researchers and participants and mutual
3134 benefit in researcher-community relations.

3135 The desire to conserve and develop knowledge specific to First Nations, Inuit and Métis
3136 communities, and to benefit from modern applications of traditional knowledge, is a
3137 motivating force in community initiatives to assume a decisive role in research. The
3138 guidance provided in this chapter is based on the premise that engagement with community
3139 is an integral part of ethical research involving Aboriginal people. While continuing to
3140 respect individual autonomy, this Policy acknowledges the role of community in shaping the
3141 conduct of research, in particular, research that affects First Nations, Inuit and Métis
3142 peoples. In light of the diversity within and between First Nations, Inuit and Métis
3143 communities, and the ongoing development of community codes of research practice by
3144 these communities at the local, regional and national level, ethical review of a proposed
3145 project must be attentive to its specific context.

3146 This chapter has drawn on prior work, both within Canada and internationally, that
3147 recognizes the rights, interests and responsibilities of Aboriginal peoples participating in and
3148 affected by research endeavours. Some of that work has been done by the three agencies
3149 responsible for this Policy. In particular, the Canadian Institutes of Health Research (CIHR)
3150 and its Institute of Aboriginal Peoples’ Health have engaged in extensive dialogue with
3151 community partners to develop CIHR *Guidelines for Health Research Involving Aboriginal*
3152 *People* (2007). The Social Sciences and Humanities Research Council (SSHRC) and the

3153 Natural Sciences and Engineering Research Council (NSERC) likewise have developed
3154 guidelines applicable to programs targeted at research involving Aboriginal people and
3155 issues. Aboriginal entities at local, regional and national levels have published and
3156 implemented codes governing research practice, including ethical protections, that
3157 emphasize collective rights, interests and responsibilities.

3158 This Policy provides guidance for research involving humans, as defined in Chapter 2
3159 (“Scope and Approach”). Guidelines applicable to particular programs, research domains
3160 and community settings may elaborate on processes set out herein, or may address ethical
3161 concerns of broader scope. Researchers and research ethics boards (REB) are advised to
3162 consult reference documents that apply to their research undertaking. Examples of relevant
3163 resources are listed at the end of this chapter.

3164 **A. Key Concepts and Definitions**

3165 This chapter uses the following key concepts:

3166 **Aboriginal peoples:** A term used in the *Constitution Act*, 1982, referring collectively to
3167 Indian (First Nations), Inuit and Métis peoples, whose existing Aboriginal and treaty rights
3168 are affirmed and protected. For the purposes of this Policy, this term includes persons of
3169 First Nations, Inuit or Métis origin regardless of where they reside and whether or not they
3170 have status on an official register. The term “Aboriginal” glosses over the distinctions
3171 among First Nations, Inuit and Métis peoples, who have their own distinct histories, cultures
3172 and languages, so an attempt has been made to limit use of the term in this Policy to
3173 instances where a global term is appropriate.

3174 **Aboriginal rights, interests and responsibilities:** For the purposes of this Policy, ethical
3175 obligations are more broadly construed than the legal definition of Aboriginal and treaty
3176 rights. The term “responsibilities” is consistent with Aboriginal worldviews that include
3177 multi-generational obligations to ancestors and future generations.

3178 **Community:** A term used to describe a collectivity with shared identity or interests that has
3179 the capacity to act or express itself as a group. In this Policy, a community may be
3180 territorial, organizational or a community of interest. Territorial communities have
3181 governing bodies exercising local or regional jurisdiction, for example, members of a First
3182 Nation resident on reserve lands. Organizational communities have explicit mandates and
3183 formal leadership. In both territorial and organizational communities, membership is defined
3184 and the community has designated leaders. Communities of interest may be formed by
3185 individuals or organizations who come together for a common purpose or undertaking, such
3186 as a commitment to conserving a heritage language. These are informal communities, whose
3187 boundaries and leadership may be fluid and less well-defined. They may exist temporarily or
3188 over the long term.

3189 An individual may belong to multiple communities, both Aboriginal and non-Aboriginal, for
3190 example as a member of a local Métis community, a graduate students’ society, and a
3191 coalition in support of Aboriginal rights. For the purposes of research, how an individual

3192 defines which of his or her community relationships are most relevant will likely depend on
3193 the nature of the particular research project being proposed.

3194 **Community engagement:** Community engagement is a process that establishes interaction
3195 between a researcher or research team and the Aboriginal community relevant to the
3196 research project. It signifies a collaborative relationship between researchers and
3197 communities, although the degree of collaboration may vary depending on the community
3198 context and the nature of the research. The engagement may take many forms, including:
3199 consent from formal leadership to conduct research in the community; joint planning with a
3200 responsible agency; commitment to a partnership formalized in a research agreement; or
3201 dialogue with an advisory group expert in the customs governing the knowledge being
3202 sought. The level of engagement may range from information sharing to active participation
3203 and collaboration to empowerment and shared leadership of the research project.
3204 Communities may also choose not to engage actively in a research project, but simply to
3205 acknowledge it and register no objection to it.

3206 **Indigenous knowledge** is the term in common usage internationally to refer to the
3207 knowledge held by Indigenous peoples who, in Canada, may be referred to as Aboriginal.
3208 Indigenous knowledge is usually described as holistic, involving body, mind, feelings and
3209 spirit. Knowledge is specific to place, transmitted orally and rooted in the experience of
3210 multiple generations. Indigenous knowledge is expressed in symbols, arts, ceremonial and
3211 everyday practices, narratives and especially, in relationships. Indigenous peoples value
3212 their relationship with the land as a living entity that reveals the way to living a good life.
3213 Spirituality expressed in traditional or Christian practices, relationships with ancestors and
3214 responsibilities to coming generations are integral to the worldview of many Aboriginal
3215 peoples.

3216 Indigenous knowledge has gained recognition as a resource of potential benefit to modern
3217 society – for example, through traditional techniques of sustaining environmental systems in
3218 balance with human usage or knowledge of plant life for agricultural, medicinal and
3219 cosmetic purposes. It includes traditional knowledge received from past generations and
3220 innovations transmitted to subsequent generations.

3221 **B. Interpreting the Ethics Framework in First Nations, Inuit and Métis** 3222 **Contexts**

3223 Chapter 1 (“Ethics Framework”) identifies three principles as expressions of the core ethical
3224 value of respect for human dignity: respect for persons, concern for welfare and justice. The
3225 three core principles are interpreted in this chapter as follows:

3226 **Respect for persons** is expressed principally through securing the voluntary, informed
3227 consent of research participants. First Nations, Inuit and Métis concerns for their continuity
3228 as peoples with distinctive cultures and identities have increasingly led to the development
3229 of codes of research practice that address concerns arising from their worldviews.
3230 Aboriginal codes of research practice thus go beyond the scope of ethical protections for
3231 individual participants, and extend to the interconnection between humans and the natural

3232 world, as well as obligations to maintain and pass on to future generations knowledge
3233 received from ancestors and innovations devised in the present generation.

3234 Historically, the well-being of individual participants has been the focus of research ethics
3235 guidelines. In this Policy, the principle of concern for **welfare** is broader, requiring
3236 consideration of participants and potential participants in their physical, social, economic,
3237 and cultural environments. This Policy acknowledges the important role of Aboriginal
3238 communities in promoting collective rights, interests and responsibilities that also serve the
3239 welfare of individuals.

3240 Aboriginal peoples are particularly concerned that research should enhance their capacity to
3241 maintain their cultures, languages and identities as distinct peoples and to facilitate their full
3242 participation in and contribution to Canadian society. The interpretation of concern for
3243 welfare in First Nations, Inuit and Métis contexts may therefore place strong emphasis on
3244 collective welfare as a complement to individual well-being.

3245 **Justice** may be compromised when a serious imbalance of power prevails between the
3246 researcher and participants. Resulting harms are seldom intentional but nonetheless real for
3247 the research participants. In the case of Aboriginal peoples, abuses stemming from research
3248 have included: appropriation of cultural heritage such as songs, stories and artefacts;
3249 devaluing of Indigenous knowledge as primitive or superstitious; violation of community
3250 norms regarding the use of human tissue and remains; and dissemination of information that
3251 misrepresented or stigmatized whole communities.

3252 Where the social, cultural or linguistic distance between the community and researchers
3253 from outside the community is significant, the potential for misunderstanding is likewise
3254 significant. Engagement between the community involved and researchers, initiated prior to
3255 recruiting participants and maintained over the course of the research, can enhance ethical
3256 practice and the quality of research. Taking time to establish a relationship can promote
3257 mutual trust and communication, identify mutually beneficial research goals, define
3258 appropriate research collaborations or partnerships, and ensure that the conduct of research
3259 adheres to the principles of justice, respect for persons and the concern for welfare of the
3260 collective, as understood by all parties involved.

3261 **Research Involving Indigenous Peoples in Other Countries**

3262 **Indigenous peoples** is a term used in international discourse, roughly equivalent to the
3263 umbrella term Aboriginal peoples in Canada. Indigenous people are the descendants of those
3264 who inhabited a country or a geographical region prior to the time when people of different
3265 cultures or ethnic origins arrived and established dominance through conquest, occupation
3266 or settlement. They display resolve to maintain and adapt their heritage and historical links
3267 to their territories and associated natural resources.

3268 Although the present chapter addresses research involving Aboriginal peoples in Canada,
3269 researchers, research ethics boards (REBs), research participants and the research
3270 community at large may find the guidance articulated here useful when undertaking research
3271 or reviewing a proposal involving Indigenous peoples in other countries or ethno-cultural

3272 groups who endorse collective decision-making as a complement to individual consent.
3273 However, the importance of seeking local guidance in applying or adapting ethical
3274 guidelines articulated in this Policy must be emphasized.

3275 For considerations that apply to research conducted in another country, see Sections B and C
3276 in Chapter 8 (“Multi-Jurisdictional Research”).

3277 **C. Applying Provisions of this Policy in Aboriginal Contexts**

3278 **The Requirement of Community Engagement in Aboriginal Research**

3279 **Article 9.1** Where the research is likely to affect a community or communities to which
3280 potential participants belong, and where any of the following conditions
3281 apply, researchers shall seek engagement with the relevant community:

3282 (a) Research is conducted on First Nations, Inuit or Métis lands;

3283 (b) Recruitment criteria include Aboriginal identity as a factor for the entire
3284 study or for a subgroup in the study;

3285 (c) The research seeks input from participants regarding a community’s
3286 cultural heritage, artefacts, Indigenous knowledge or unique
3287 characteristics;

3288 (d) Aboriginal identity or membership in an Aboriginal community is used as
3289 a variable for the purpose of analysis of the research data;

3290 (e) The interpretation of the research results will refer to Aboriginal
3291 communities, peoples, language, history or culture.

3292
3293 **Application** While the legal basis for research oversight may vary depending on the
3294 community, the practical requirement of engaging community representatives
3295 and the ethical obligation to respect community views of welfare remain
3296 consistent.

3297
3298 Paragraph (a) refers to First Nations, Inuit and Métis lands that include Indian
3299 reserves, Métis settlements, lands allocated under an Inuit or First Nations
3300 land claim agreement and lands over which a claim has been asserted but not
3301 settled, as defined by the Aboriginal community prospectively engaged in
3302 research.

3303
3304 Paragraph (c) refers to cultural heritage, which includes but is not limited to
3305 First Nations, Inuit and Métis peoples’ relations with particular territories,
3306 material objects, collective knowledge and skills, and intangibles that are
3307 transmitted from one generation to the next – such as folklore, customs,
3308 representations or practices. Cultural heritage is a dynamic concept, in that
materials, knowledge and practices are continuously adapted to the realities of

3309 current experience. For further discussion of cultural heritage see, for example,
3310 the United Nations *Declaration on the Rights of Indigenous Peoples* cited under
3311 References at the end of this chapter.

3312 Cultural heritage research such as archaeological research and handling of
3313 artefacts may raise ethical obligations important to the Aboriginal community
3314 that may not be addressed in academic research protocols. Researchers and
3315 communities should agree in advance on how to reconcile or address these
3316 divergent perspectives (see Article 9.12).

3317 Paragraph (c) also refers to Indigenous knowledge. Appropriation of Indigenous
3318 knowledge, treatment of such knowledge as a commodity to be traded, or
3319 making unauthorized adaptations for commercial purposes may cause offence or
3320 harm to communities from which the knowledge originates. Such violations
3321 have prompted initiatives in various countries and international agencies to
3322 prevent unethical exploitation of Indigenous knowledge and knowledge holders
3323 (see Article 9.18, “Intellectual Property and Copyright”).

3324 **Forms of Engagement**

3325 Community engagement as defined in this Policy can take varied forms. In geographic and
3326 organizational communities that have local governments or formal leadership, engagement
3327 would normally take the form of review and approval of a research proposal by a designated
3328 body prior to recruiting participants. In less structured situations, for example a community of
3329 interest, a key consideration for researchers, prospective participants and research ethics boards
3330 (REBs) is determining the nature and extent of community engagement required. In some
3331 situations the determination may be that the welfare of relevant communities is not affected and
3332 voluntary, informed consent of individuals is sufficient. Communities lacking infrastructure to
3333 support community engagement should not be deprived of opportunities to participate in
3334 guiding research affecting their welfare (see Article 9.14, “Strengthening Research Capacity”).

3335 **Article 9.2** The nature and extent of community engagement in a project shall be
3336 determined jointly by the researcher and the relevant community and shall be
3337 appropriate to community characteristics and the nature of the research.

3338 **Application** First Nations, Inuit and Métis communities differ from one another, and they
3339 encompass increasing diversity within their own boundaries as a result of formal
3340 education, employment, mobility and intermarriage with non-Aboriginal
3341 persons. This diversity makes generalizations about the form of community
3342 engagement inappropriate. It also increases the importance of clarifying mutual
3343 expectations and obligations with the community and incorporating them in a
3344 research agreement.

3345 The following list, which is not exhaustive, provides examples to illustrate
3346 the forms of Aboriginal engagement that might be appropriate in various
3347 types of research.

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- 1) Research directly involving a community on First Nation, Inuit or Métis lands with a formal governance structure. For example, a project that examines the incidence of diabetes in Pond Inlet or the impact on Inuit health of contaminants in animals and plants used for country food.
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- Permission of the land claims organization that carries authority to approve research in Nunavut is required. Agreement of the hamlet council in Pond Inlet will normally be a condition of approval. The local health committee may co-manage the project.
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- 2) Research involving Aboriginal people who comprise a sizeable proportion of the study or community and where Aboriginal-specific conclusions are intended. For example, a comparative study of access to public housing in Prince Albert, Saskatchewan.
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- First Nations in the district, represented by their tribal council, the local Métis association, urban Aboriginal and women's organizations may partner with the Prince Albert city council to sponsor, implement and use the results of the housing study.
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- 3) Research focusing on a larger community which is known to include Aboriginal people (regardless of their proportion), and where Aboriginal-specific conclusions are anticipated. For example, a study of student retention in high schools in the Sault Ste. Marie district of Ontario.
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- A committee to advise the District Board of Education and the researchers conducting the retention study may be convened, representing First Nations, Métis organizations and urban Aboriginal people whose children are affected.
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- 4) Research involving Aboriginal people who comprise a sizeable proportion of the larger community that is the subject of research even if no Aboriginal-specific conclusions will be made. For example, research on employment development programs serving residents of Winnipeg's inner city.
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- Aboriginal service agencies or political organizations may be engaged to help recruit Aboriginal participants and secure community representation on an oversight committee, to ensure cultural sensitivity in collecting and interpreting data on employment program impacts.
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- 5) Interviewing a sample of individuals of Aboriginal ancestry across Canada on the impact of a policy in their lives, where the results are not attributable to or likely to affect the community or communities with which they may identify. For example, survey research on the

- 3387 implementation of Indian Act provisions requiring ministerial approval of
3388 an “Indian’s” will.
- 3389 ▪ First Nations, Inuit and Métis individuals, whether or not they identify
3390 as members of an Aboriginal community, enjoy freedom of
3391 expression as does any citizen. They are free to give informed consent
3392 and to participate in research projects that they consider of personal or
3393 social benefit. If the project is unlikely to affect the welfare of the
3394 individuals’ communities, local community engagement is not
3395 required under this Policy. The necessity or desirability of engaging
3396 regional or national representatives of Aboriginal communities in
3397 policy research may, however, be determined by other considerations.
- 3398 6) Natural sciences research on First Nation or Inuit lands where Aboriginal
3399 people may act as co-investigators or benefit from findings. For example,
3400 research focusing exclusively on contaminants in animals or plants in
3401 Nunavik that does not make inferences regarding food intake.
- 3402 ▪ Research that involves the collection and analysis of tissue samples
3403 from animals or plants and not involving human research participants
3404 is not covered within the scope of this Policy and does not require
3405 REB review. However, funding program guidelines and licensing
3406 requirements in the North may impose obligations to engage
3407 communities. Community laws, customs or codes of research practice
3408 may require securing regional and local permission and reporting
3409 findings to communities on whose traditional lands the research takes
3410 place. (See NSERC literature on Northern Research Program for
3411 professors and students/fellows and Article 9.8 below.)
- 3412 7) Research that incidentally involves a small proportion of Aboriginal
3413 individuals but is not intended to single out or describe characteristics of
3414 Aboriginal people in the study. For example, a study of the effectiveness
3415 of therapies to control high blood pressure in a sample of hospital
3416 outpatients not designed to collect Aboriginal-specific data.
- 3417 ▪ Since Aboriginal participation is incidental rather than scheduled,
3418 community engagement is not required. If Aboriginal individuals self-
3419 identify during the collection of primary data, researchers should
3420 inquire whether culturally appropriate assistance is desired to interpret
3421 or support compliance with study protocols. However, it should be
3422 noted that including markers of Aboriginal identity in data collection
3423 may reveal anomalies that warrant further, more targeted research,
3424 which would require community engagement.
- 3425 8) Research exclusively based on publicly available information as defined
3426 by this policy. For example, historical, genealogical or analytical research

3427 based exclusively on publicly available records or data in accordance
3428 with statutes.

3429 ▪ Such research does not involve the collection of data from
3430 communities directly or from living persons and is not subject to REB
3431 review (see Article 2.2 in Chapter 2 [“Scope and Approach”]).
3432 Community engagement is not required. However, findings of such
3433 research nevertheless may have an impact on the identity or heritage
3434 of persons or communities. Researchers should seek culturally
3435 informed advice before use of such data to determine if harms may
3436 result and if benefit-sharing should be explored with the original
3437 source community. (See Article 9.15)

3438 **Respect for Jurisdiction on First Nation, Inuit and Métis Lands**

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3440 **Article 9.3** Where a proposed research project is to be conducted on lands under the
3441 jurisdiction of a First Nation government, an Inuit land claim organization or a
3442 Métis government, or on traditional lands subject to a claim as defined by the
3443 community, researchers shall seek the engagement of formal leaders of the
3444 community, except as provided under Articles 9.5, 9.6 and 9.7.

3445 **Application** Formal leaders with governance responsibilities on First Nations, Inuit or Métis
3446 lands are charged with protecting the welfare of the community. They may
3447 approve research or delegate responsibility for reviewing proposals to a local or
3448 regional body. Article 8.4 in Chapter 8 (“Multi-Jurisdictional Research”), applies
3449 in such cases, requiring ethics review of research proposals by both the research
3450 ethics board (REB) at the researcher’s institution and “by the REB or other
3451 responsible body, where such exists, [at the collaborating institution(s)] in the
3452 host research site,” Ethics review by the institutional REB and the responsible
3453 community body are required in advance of recruiting and securing consent of
3454 individuals.

3455 Research involving multiple geographic communities raises complex issues of
3456 review and approval. Regional bodies or national organizations may facilitate
3457 ethics review and make recommendations but the decision on participation
3458 normally rests with the local community.

3459 **Engagement with Organizations and Communities of Interest**

3460 **Article 9.4** Aboriginal organizations, including First Nations, Inuit and Métis representative
3461 bodies, service organizations and communities of interest shall be recognized as
3462 communities for the purposes of collaboration in research undertakings and
3463 representation of their members in ethical review and oversight of projects.

3464 **Application** Research affecting First Nations, Inuit and Métis peoples is often initiated
3465 outside the Aboriginal community and carried out by non-Aboriginal
3466 personnel. Researchers have often neglected to inform participants and
3467 communities of results and they have afforded Aboriginal people little
3468 opportunity to correct misinformation or to challenge ethnocentric
3469 interpretations. In light of such experience, many Aboriginal people feel
3470 apprehensive about the activities of researchers and they are reluctant to
3471 participate in research.

3472 A majority of persons who self-identify as Aboriginal live in rural and urban
3473 communities outside of designated Aboriginal lands. Issues affecting their
3474 welfare are under-researched. Political organizations, Friendship Centres,
3475 housing associations, healing circles and many other groups that have come
3476 together are potential partners in creating knowledge to enhance the welfare
3477 of their own communities and society at large.

3478 **Complex Authority Structures**

3479 **Article 9.5** Where alternatives to securing the agreement of formal leadership are proposed
3480 for research on First Nations, Inuit or Métis lands or in organizational
3481 communities, researchers should engage community processes and document
3482 measures taken, to enable the research ethics boards (REBs) to review the
3483 proposal with due consideration of complex community authority structures.

3484 **Application** Research ethics boards should not assume that approval of a project by formal
3485 leaders is the only avenue for endorsing a project. In some communities and
3486 some domains of knowledge, authority to permit and monitor research rests with
3487 knowledge keepers designated by custom rather than election or appointment. In
3488 First Nations settings, a confederacy council spanning several communities may
3489 be recognized as having authority over its members' traditional knowledge. In
3490 an Inuit community, the hamlet council, an Elders' circle and a Hunters and
3491 Trappers society may have overlapping responsibility and expertise with respect
3492 to the knowledge being sought. Métis Elders dedicated to conserving Michif
3493 language may assert their autonomy from political leaders but choose to
3494 collaborate with educational or cultural agencies.

3495 The preferred course is to secure approval for research from both formal leaders
3496 of a community and customary authority. This is especially important for
3497 outsiders to communities, whose presence or intentions might be challenged.
3498 Researchers should engage community processes, including the guidance of
3499 moral authorities such as Elders, to avert potential conflict. These measures
3500 should be documented to assist the REB in considering the community
3501 engagement processes proposed (see Article 9.10, "Requirement to Advise REB
3502 on Plan for Community Engagement").

3503 **Recognizing Diverse Interests Within Communities**

3504 **Article 9.6** In engaging communities, researchers should ensure, to the extent possible,
3505 that they take into consideration the views of all relevant sectors, including
3506 communities of interest who may not have a voice in the formal leadership of
3507 a geographical or organizational community. Vulnerable groups or
3508 individuals may need or desire special measures to ensure their safety or
3509 inclusion.

3510 **Application** Vulnerable or marginalized subgroups within communities should be not be
3511 deprived of opportunities to participate in guiding research affecting their
3512 welfare. Covert research or direct challenges to legitimate authority risk
3513 increasing participants’ vulnerability, deepening rifts within the community and
3514 actually impeding the advancement of social justice. Strategies that have proven
3515 effective to accommodate diversity include: advocacy by moral authorities in
3516 the community; special measures to protect the identity of participants in small
3517 communities; identifying research questions that include rather than divide
3518 interest groups; or expanding the coverage of a project to multiple communities
3519 where personal interests are less prominent. In some cases, the risks to
3520 participants and communities involved with or affected by the proposed research
3521 outweigh the benefits likely to be gained and the research should not be
3522 undertaken.

3523 **Critical Inquiry**

3524 **Article 9.7** Research that critically examines the conduct of public institutions or persons in
3525 authority may do so ethically, notwithstanding the usual requirement, in
3526 research involving Aboriginal peoples, of engaging representative leaders.

3527 **Application** Considerations in conducting critical inquiry are discussed more fully in
3528 Article 3.6 of Chapter 3 (“Free and Informed Consent”). As in the case of
3529 research involving vulnerable subgroups within an Aboriginal community
3530 (see Article 9.6) critical inquiry will require creative approaches to ensure
3531 that cultural norms are respected, that the safety of participants is protected
3532 and that the welfare of the larger community is not disrupted.

3533 For example, the Sisters in Spirit project of the Native Women’s Association
3534 of Canada (NWAC) launched in 2005 for a five-year period illustrates
3535 research of national scope that incorporates a critical dimension. The project
3536 involves interviewing families of missing and murdered Aboriginal women in
3537 urban and rural settings, on and off First Nations territory. It examines,
3538 among other matters, the adequacy of public institutions and services,
3539 Aboriginal and non-Aboriginal, to protect the women’s well-being and
3540 support families in their efforts to deal with their losses. The objective is to
3541 effect policy change and improve the safety and well-being of Aboriginal
3542 women in Canada. NWAC has published its commitment to participatory

3543 research and the principles and practices that protect privacy and well-being
3544 of participants. The project builds on NWAC’s established moral authority to
3545 investigate sensitive matters, welcomes endorsement by a national political
3546 organization, engages the cooperation of regional health directors where
3547 available, and informs local authorities of the presence of its researchers on
3548 First Nations territory.

3549 **Respect for Community Customs and Codes of Practice**

3550 **Article 9.8** Researchers have an obligation to become informed about and to respect the
3551 relevant customs and codes of research practice that apply in the particular
3552 community or communities affected by their research. Inconsistencies between
3553 community custom and this Policy should be identified and addressed, where
3554 possible, in advance of initiating the research.

3555 **Application** First Nations, Inuit and Métis codes of research practice derive from laws and
3556 customs of predominantly oral cultures. While some rules may be in written
3557 form, their interpretation is dependent on experiential knowledge acquired
3558 through interactions in the community. An example is the strict limitation on
3559 making publicly available sacred knowledge which might be revealed within a
3560 trusting relationship. In academic culture, rules regarding limits on disclosure of
3561 information would reasonably be incorporated in a research protocol.

3562 In Aboriginal communities, custom may restrict the observation, recording or
3563 reporting of ceremonies or certain performances and require approval of
3564 appropriate individuals. Article 10.3 addresses research involving observational
3565 studies, the requirement for research ethics review and the ethical implications
3566 associated with observational research approaches, which may infringe on free
3567 and informed consent and privacy.

3568 Many First Nations communities across Canada have adopted an ethics code
3569 originally developed to govern practice in the First Nations Regional Health
3570 Survey. It asserts ownership, control, access and possession of research
3571 processes affecting participant communities and is generally referred to as
3572 OCAP. It addresses issues of privacy, intellectual property, data custody and
3573 secondary use of data, which are also covered later in this chapter. Researchers
3574 should consult with their own institutions to ensure that compliance with OCAP
3575 or other community-based ethics codes is consistent with institutional policies,
3576 particularly on issues of intellectual property. Where conflicts exist, they should
3577 be addressed and resolved prior to the commencement of the research. (See
3578 Article 9.18)

3579 The obligation to respect community laws, customs and responsibilities and to
3580 engage the relevant community applies to First Nations, Inuit and Métis
3581 researchers conducting research in their own local or cultural communities, if
3582 they are also members of research institutions adhering to this Policy. First
3583 Nations, Inuit and Métis scholars attached to academic institutions as faculty

3584 members, students or research associates are increasingly engaged in research
3585 involving their own communities and sometimes their own family members.
3586 They are generally exempt from restrictions on physical access to territory or
3587 personal access to community members.

3588 Life history and language research are examples of research areas where insider
3589 relationships and skills provide unique opportunities to extend the boundaries of
3590 knowledge. While it can be argued that recording the life history of an elderly
3591 relative is a family matter rather than a community matter, the potential impact
3592 of such research on the wider community, conflicts between the individualist
3593 norms of the academic environment and the norms of the community, and the
3594 possibility of unclear or mistaken assumptions on the part of participant and
3595 researcher make community engagement important. The relevant community to
3596 be engaged in such cases might be extended family members, peers of the
3597 participant with whom the researcher’s interpretations can be validated, or
3598 Elders knowledgeable about cultural rules governing disclosure of privileged
3599 information.

3600 **Institutional Ethics Review Required**

3601 **Article 9.9** Ethics review by community research ethics boards (REBs) or other responsible
3602 bodies at the research site will not be a substitute for review by institutional
3603 REBs and will not exempt researchers affiliated with an institution from seeking
3604 REB approval at their institution, subject to Article 8.1.

3605 **Application** Applying this Policy in a way that accommodates the diversity of First Nations,
3606 Inuit and Métis cultures and communities is complex. For example, the fit
3607 between institutional policies and community laws, customs and codes of
3608 research practice may be unclear, requiring researchers to adapt conventional
3609 practice or negotiate a resolution.

3610 The presumption that community engagement is required in research involving
3611 Aboriginal participants is consistent with Article 8.4, which provides that
3612 research conducted outside the jurisdiction of the researcher’s institution “shall
3613 undergo prospective ethics review both by the REB at the Canadian institution
3614 under the auspices of which the research is being conducted and by the REB or
3615 similar body, where such exists, [at the collaborating institutions(s)] in the host
3616 research site.”

3617 Article 8.1 permits review models for multi-site research that do not require
3618 separate ethics review by each site involved in a research project. In cases where
3619 the community is the direct recipient of funding and has constituted a local REB
3620 that is party to such an agreement with the researcher’s institution, review by the
3621 institution’s REB may not be required. (See Article 8.1 in Chapter 8, [“Multi-
3622 Jurisdictional Research”].)

3623 In accordance with Article 8.4, communication between the institutional REB

3624 and the responsible agency in the community may assist in resolving
3625 inconsistencies between institutional policy and community laws, customs and
3626 codes of research practice. If a community ethics review is required in addition
3627 to the mandatory institutional REB review, reconciling differences may require
3628 re-submission to one or the other review body.

3629 Researchers and REBs should recognize that ethics review by community
3630 bodies will often pursue purposes and apply criteria that differ from the
3631 provisions of this Policy. The express purpose of most Aboriginal community
3632 codes of research practice is to ensure relevance of research undertakings to
3633 community needs and priorities and respect for First Nations, Inuit and Métis
3634 identities, cultures and knowledge systems. While community codes of practice
3635 and research agreements typically share many of the goals of institutional
3636 policies, the approaches to achieving those goals may differ significantly. It is
3637 therefore inappropriate to insist on uniformity between community practices and
3638 institutional policies. For example, when researchers seek to interview Elders
3639 willing to share their knowledge according to traditional customs of consent,
3640 REBs should not impose language and processes that may be experienced as
3641 culturally inappropriate or awkward.

3642 In cases where review of research on topics related to Aboriginal peoples is
3643 regularly required, the REB membership should be modified to ensure that
3644 relevant and competent knowledge and expertise in Aboriginal cultures are
3645 captured within its regular complement. For occasional review of Aboriginal
3646 research appointment of ad hoc advisors or delegation to a specialized or
3647 multi-institutional REB may be appropriate. (See Articles 6.4, 6.5 in Chapter
3648 6 [“Governance of Research Ethics”] and Article 8.1 in Chapter 8 [“Multi-
3649 Jurisdictional Research”].)

3650 The membership of community review bodies of First Nations, Inuit or Métis
3651 communities will not necessarily duplicate the membership criteria set out in
3652 this Policy. In the context of scarce resources in community organizations, the
3653 same personnel may be involved in reviewing the ethics of a proposal and co-
3654 managing the research. An expectation that conflict of interest will be managed
3655 by separating ethics review and project management functions may impose
3656 unsupportable demands on small communities. Researchers and participating
3657 Aboriginal communities should address how in those circumstances ethical
3658 safeguards of the community and its members are best achieved when multiple
3659 roles are assumed by the same person. (See Chapter 7 [“Conflict of Interests”].)

3660 **Requirement to Advise the Research Ethics Board on Plan for Community Engagement**

3661 **Article 9.10** When proposing research expected to involve First Nations, Inuit or Métis
3662 participants, researchers shall advise their research ethics board (REB) how they
3663 have engaged or intend to engage the relevant community or, alternatively,
3664 present a rationale as to why an exception to the requirement is appropriate.

3665 **Application** In order for REBs to consider whether the form of community engagement is
3666 appropriate, they will require evidence in the form of (a) a preliminary or formal
3667 research agreement between the researchers and the responsible body in the
3668 research site; (b) documentation of a written or oral decision to approve the
3669 proposed research in a group setting; (c) a written summary of advice received
3670 from a culturally informed advisory group or ad hoc committee, for example in
3671 an urban community of interest. Provision of a research agreement is
3672 particularly emphasized in health research funded by CIHR (see CIHR
3673 *Guidelines for Health Research Involving Aboriginal People* in Reference
3674 section at end of this chapter).

3675 Where a researcher has an ongoing relationship with a community, a letter
3676 from formal or customary leaders in the relevant community may signal
3677 approval to proceed with the research.

3678 Although researchers must offer the option of engagement, a community may
3679 choose to engage nominally or not at all, despite being willing to allow the
3680 research to proceed. A community may, for example, support a study carried
3681 out independent of community influence in order to use scientifically
3682 defensible results to validate a negotiating position. In instances where
3683 community engagement is not taken up, researchers must present to the REB
3684 the steps they took to invite and facilitate engagement by the community.
3685 Lack of engagement by communities may also be due to inadequate financial
3686 or human resources. Researchers should demonstrate what efforts they have
3687 made to assist in capacity-building to facilitate engagement.

3688 **Research Agreements**

3689 **Article 9.11** Where a community has formally engaged with a researcher or research team
3690 through a designated representative, the terms and undertakings of both the
3691 researcher and the community should be set out in a research agreement before
3692 participants are recruited.

3693 **Application** Research agreements serve as a primary means of clarifying and confirming
3694 mutual expectations and, where appropriate, commitments between researchers
3695 and communities. The scope of the agreement will depend on the level of
3696 engagement which the community desires, and the availability of resources to
3697 support community participation.

3698 At a minimum, the agreement should address the ethical protections that would
3699 apply in securing individual consent for a comparable project and should specify
3700 any commitments regarding collective community participation and decision-
3701 making, sharing of benefits and review and updating of the agreement.
3702 Expanding on information normally provided to an individual participant (see
3703 Article 3.2), agreements typically set out the purpose of the research and detail
3704 mutual responsibilities in project design, data collection and management,
3705 analysis and interpretation, production of reports and dissemination of results.

3706 Where a community has adopted or adheres to a code of research practice the
3707 agreement may set out detailed responsibilities. In less formal circumstances,
3708 the agreement may be relatively brief and subject to clarification as the
3709 project unfolds. CIHR *Guidelines for Health Research Involving Aboriginal*
3710 *People* (2007) provide examples of elements that may be included in research
3711 agreements (see Reference section at the end of this chapter).

3712 Research agreements are increasingly being recognized by academic
3713 institutions and the researchers associated with them as providing reference
3714 points for ethics review and approval on such elements as consent,
3715 confidentiality and intellectual property. Agreements that specify procedures
3716 for community ethics review, included as part of the institutional ethics
3717 application, can provide contextual information and guidance for REBs
3718 conducting initial review of applications and continuing ethics review
3719 throughout the project. Researchers should check with their institutions
3720 regarding signing authority for research agreements that include undertakings
3721 beyond those normally included in a consent form.

3722 Community agreement that a research project may proceed is not a substitute
3723 for securing the free and informed consent of individuals being recruited to
3724 participate in that project, in accordance with Chapter 3 (“Free and Informed
3725 Consent”).

3726 Building relationships, clarifying the goals of a project and negotiating
3727 agreements requires substantial investment of time and resources on the part
3728 of the community and researcher. Development and participation costs
3729 incurred by the community and the researcher should be factored into
3730 proposals to the extent possible within funding guidelines.

3731 Collaborative Research

3732 **Article 9.12** While community engagement is appropriate in any research that affects
3733 Aboriginal communities, researchers should consider applying a
3734 collaborative or participatory approach as appropriate to the nature of the
3735 research and the level of engagement desired by the community.

3736 **Application** This Policy encourages collaborative research with First Nations, Inuit and
3737 Métis communities as a means of facilitating mutually respectful and
3738 productive relations.

3739 Collaborative research is generally understood to involve respectful
3740 relationships among colleagues, each bringing distinct expertise to a project.
3741 Collaboration often involves one or other of the partners taking primary
3742 responsibility for certain aspects of the research, such as addressing sensitive
3743 issues in community relations or scientific analysis and interpretation of data.

3744 Community-based research is research that takes place at community sites and

3745 involves collaboration between community agencies and scientific researchers.
3746 It often seeks to address a research topic of practical relevance to the
3747 community. The terms “community-based research” and “participatory
3748 research” are often used interchangeably or in combination.

3749 Participatory research is a method that promotes research relevant to local
3750 concerns, action and social change, increased community skills, capacity
3751 building, sustainability, and knowledge translation. In its fullest expression,
3752 participatory research engages researchers and community members in an active
3753 partnership that shares decision-making throughout the research process:
3754 identifying the issue to be researched, developing the research design,
3755 collecting, analyzing, and interpreting the data, developing conclusions and
3756 disseminating results.

3757 An outcome of collaborative research highly valued by communities is
3758 increased capacity to carry out autonomous research that can more readily be
3759 conducted in Aboriginal languages and oral modes. The exploration,
3760 articulation and application of Indigenous knowledge in the local community
3761 is thus advanced, potentially benefiting other communities through
3762 knowledge transfer.

3763 **Mutual Benefits in Collaborative Research**

3764 **Article 9.13** Collaborative research should be relevant to community needs and priorities
3765 and should benefit the participating community as well as extend the
3766 boundaries of societal knowledge.

3767 **Application** To benefit the participating community a research project should be relevant
3768 and have the potential to produce valued outcomes from the perspective of
3769 the community and its members.

3770 Relevance and community benefit can take a number of forms depending on
3771 the type of research being conducted. For example, genetic research on
3772 diabetes in a First Nations community is unlikely to benefit the community in
3773 the short term, but collaboration may facilitate increased knowledge of the
3774 condition and change that improves health outcomes. Collaborative research
3775 can thus accommodate basic as well as applied research, short-term and long-
3776 term benefits. In another example, a study of housing and homelessness in an
3777 Inuit community was initiated at the request of the community. Using
3778 participatory research methods and social science tools, the nature, extent and
3779 consequences of the local housing shortage was documented, enabling the
3780 community to communicate its needs effectively to non-Inuit (Qallunaat)
3781 authorities. Training workshops provided employment and transferred skills
3782 to Inuit youth involved in data collection. The project provided field
3783 experience in community-based research for university student assistants and
3784 materials useful to other Inuit communities in subsequent research.

3785 Communities participating in research place a high priority on access to
3786 research data that will allow them to address pressing issues through
3787 community-generated policies, programs and services. They also seek to
3788 share in the benefits of research activities in the form of direct research
3789 grants, release time for project personnel, overhead levies on shared projects
3790 and commercialization of research discoveries.

3791 **Strengthening Research Capacity**

3792 **Article 9.14** Research projects should support the enhancement of the skills of community
3793 personnel in research methods, project management and ethical review and
3794 oversight.

3795 **Application** To the degree possible, researchers should foster education and training of
3796 community members to enhance their participation in research projects.
3797 Employing Aboriginal research assistants and translators is already common
3798 practice in community-based projects. Extending skills transfer through a
3799 rational program of training will support collaboration with institutions and
3800 advance the capacity of communities to initiate and implement their own
3801 research.

3802 Communities vary widely in the level of human and material resources they
3803 have available to collaborate with research initiatives. Small, remote
3804 communities and many urban communities of interest have limited
3805 organizational resources to advise or collaborate in research. The least
3806 organizationally developed communities are the most vulnerable to
3807 exploitation. Researchers, research ethics boards (REBs) and communities
3808 leaders should strive to protect the interests of such communities by
3809 undertaking research and supporting the enhancement of capacity to
3810 participate in research.

3811 Funding programs that target the development of Aboriginal research and
3812 capacity building seek to generate significant research training opportunities
3813 for Aboriginal students, allowing researchers to include in their grant
3814 applications stipends for undergraduate, master's degree or doctoral students
3815 or postdoctoral researchers, as appropriate, with priority given to Aboriginal
3816 people.

3817 **Recognition of the Role of Elders**

3818 **Article 9.15** Researchers should engage the community in determining appropriate
3819 recognition for the unique advisory role of Elders in the design and execution
3820 of research and interpretation of findings in the context of cultural norms and
3821 traditional knowledge.

3822 **Application** Recognition of Elders may include adherence to customary prescribed
3823 procedures to solicit their involvement – feasting, gift-giving, providing
3824 honoraria, acknowledging contributions by name or, as directed, withholding
3825 the Elder’s identity in reports and publications. Elders are now being
3826 recognized in research proposals and grant applications as providing access
3827 to community networks, ethical guidance to researchers, and advice in
3828 interpreting findings in the context of traditional knowledge.

3829 **Privacy and Confidentiality**

3830 **Article 9.16** Where research agreements provide that community partners will have
3831 limited or full access to identifiable personal data, the consent of participants
3832 to such disclosure shall form part of the individual consent procedure.

3833 **Application** Researchers and community partners should consider early in the design of
3834 the research how community codes of research practice fit with provisions for
3835 privacy and confidentiality set out in Chapter 5 (“Privacy and
3836 Confidentiality”). Where conflicts exist, they should be resolved in advance
3837 of starting the research.

3838 In some First Nations communities, privacy and confidentiality of
3839 identifiable personal and community information may be affected by
3840 application of the principles of ownership, control, access and possession
3841 (OCAP) (see definition under Article 9.8). The Regional Health Survey
3842 administered by regional First Nations organizations has addressed balancing
3843 confidentiality and access by having communities designate a regional
3844 organization to hold data while local authorities make decisions on who can
3845 access the data and under what conditions. In practice, the organization that
3846 serves as data steward evaluates requests for information, and its
3847 recommendations to community authorities have considerable influence.

3848 Small Aboriginal communities are characterized by dense networks of
3849 relationships, with the result that de-identifying individual data is often not
3850 sufficient to mask identities, even when data are aggregated. Communities
3851 themselves have distinguishing characteristics, which in some cases have
3852 compromised efforts to disguise the site of research and led to the
3853 stigmatization of whole communities. Some Aboriginal research participants
3854 are reluctant to speak to interviewers from their own community because of
3855 privacy concerns.

3856 On the other hand, in some social sciences and humanities research the
3857 significance of information is tied to the identity of the source and individual
3858 attribution, with consent, is appropriate. Communities partnering in research
3859 may wish to be acknowledged for their contribution.

3860 Privacy protections in research are evolving. Respect for and accommodation
3861 of First Nations, Métis and Inuit priorities on joint ownership of the products

3862 of research and maintaining access to data for community use should guide
3863 research practices, with appropriate deference to federal, provincial and
3864 territorial legislation on privacy.

3865 **Interpretation and Dissemination of Research Results**

3866 **Article 9.17** Researchers should afford community representatives engaged in
3867 collaborative research an opportunity to react and respond to research
3868 findings before the completion of the final report, in the final report, and in
3869 all relevant publications resulting from the research.

3870 **Application** Communities consider that their review and approval of reports and academic
3871 publications is essential to validate findings, protect against misinterpretation,
3872 and maintain respect for Indigenous knowledge, which may entail limitations
3873 on its disclosure. If disagreement about interpretation arises between
3874 researchers and the community and cannot be resolved, researchers should
3875 afford the group an opportunity to make its views known, or they should
3876 accurately report any disagreement about the interpretation of the data in their
3877 reports or publications.

3878 Final reports shall be made available to the community participating in the
3879 research. Researchers and communities should clarify the extent to which
3880 research findings will require translation, plain language summaries or oral
3881 presentations in order to make the research findings accessible to the
3882 community.

3883 An Aboriginal community and those who participated in the research should
3884 have the option to decide how collective or individual contributions to the
3885 research project will be acknowledged and credited in the dissemination of
3886 results, for example at conferences and seminars.

3887 **Intellectual Property and Copyright**

3888 **Article 9.18** In collaborative research, intellectual property rights and copyright should be
3889 discussed by researchers, communities and institutions in advance and
3890 assignment of rights should be specified in a research agreement as
3891 appropriate.

3892 **Application** There is an ongoing international debate regarding misappropriation,
3893 commodification, and unfair or harmful commercial exploitation of
3894 Indigenous knowledge.

3895 First Nation, Inuit and Métis laws and customs distinguish between
3896 knowledge that can be publicly disclosed, disclosed to a specific audience or
3897 disclosed under certain conditions. Researchers, institutions and communities
3898 may need to adopt a two-tiered approach, first to address issues regarding

3899 access to data and use or publication of findings, and second, to address
3900 issues related to commercial applications of the results from collaborative
3901 research. They should agree on what a researcher/student can use for
3902 publication. They should negotiate separately all intellectual property and
3903 copyright issues linked to commercial outcomes (if any) from the research.

3904 The products of collaborative research should be regarded as the intellectual
3905 property of both the researcher and the participating individuals or
3906 community, whichever is appropriate. The terms on which intellectual
3907 property and copyright are shared should be specified in a research agreement
3908 and may include limits to the disclosure of privileged information, the right to
3909 review reports and publications, attribution of authorship, intellectual
3910 property protection and retention of copyright. Arrangements for release of,
3911 or access to results can include open or restricted dissemination, joint
3912 ownership or assignment of ownership. Researchers should consult the
3913 research office of their institution before entering into a research agreement
3914 that includes copyright and intellectual property provisions. Researchers
3915 should consult the program literature or policies on intellectual property and
3916 copyright adopted by the federal research agencies NSERC, SSHRC and
3917 CIHR available on their websites.

3918 It is widely recognized that some Indigenous knowledge may have
3919 commercial applications and lead to the development of marketable products,
3920 for example, traditional plant medicines. If the proposed research has explicit
3921 commercial objectives or direct or indirect links to the commercial sector,
3922 these should be clearly communicated to all parties as a requirement of free
3923 and informed consent.

3924 The researcher and the community should openly discuss potential secondary
3925 use of traditional and sacred knowledge, and the research agreement should
3926 address how best to protect this knowledge.

3927 **Prospective Collection of Human Biological Material Involving Aboriginal Peoples**

3928 **Article 9.19** As part of community engagement, researchers shall address and specify in
3929 the research agreement, where such exists, the rights and proprietary interests
3930 of individuals and communities in human biological materials and data to be
3931 collected, stored and used in the course of the research.

3932
3933 **Application** Canadian law does not provide clear recognition of property rights in human
3934 biological materials. Researchers should be aware, however, that Aboriginal
3935 people and communities express proprietary interests in data and biological
3936 samples collected for research. Consistent with Chapter 12, and Article 9.11
3937 of this policy, researchers and communities should address and specify in the
3938 research agreement the objectives for collection, use and storage of human
3939 biological materials as well as the roles and responsibilities regarding

3940 custodianship of the data and the samples, any future use of these samples
3941 and associated data, including material transfer agreements to third parties
3942 and any subsequent requirements for community engagement.

3943
3944 Individuals who are invited to donate biological materials shall give their free
3945 and informed consent in accordance with Articles 12.1 and 12.2.

3946
3947 **Consent and Secondary Use of Data or Human Biological Materials Originating from**
3948 **Aboriginal Peoples**

3949
3950 **Article 9.20** Secondary use of data that is identifiable as originating from a specific
3951 community, or a segment of the Aboriginal community at large, requires
3952 research ethics board (REB) review and may warrant re-consent from
3953 individuals, new or renewed agreement of communities, or seeking culturally
3954 informed advice about protection of cultural heritage or representations of
3955 Indigenous knowledge or society.

3956
3957 **Application** Misrepresentation of Aboriginal peoples, unauthorized use of data or tissues,
3958 and lack of reporting to communities on research outcomes have created
3959 ongoing sensitivity about secondary use of data collected for approved
3960 purposes. For example, members of Nuu-chah-nulth communities in British
3961 Columbia provided blood samples for research on rheumatic disease. They
3962 vigorously protested use of the blood components for subsequent
3963 unauthorized genetic research. In addition, there are fears in First Nation
3964 communities that access to health data for purposes other than treatment will
3965 facilitate unauthorized government surveillance.

3966 The privacy of individual participants in research is normally protected by
3967 removing information that would identify them personally. De-identified data
3968 are added to a data pool and are available for analysis and sometimes for
3969 secondary use. Consistent with the general provisions set out in Chapter 5
3970 (“Privacy and Confidentiality”), secondary use of data collected initially for
3971 other purposes, from which personal identifiers have been removed, does not
3972 require REB review.

3973 As discussed in Chapter 5, access to data containing identifiable personal
3974 information may be needed for some types of research. For example,
3975 longitudinal studies require access to identifiable information contained in
3976 data banks, although consent for additional studies was not obtained from
3977 original informants and it may be impracticable to obtain it subsequently.
3978 Such secondary usage requires REB review (see Articles 5.5 to 5.7 in
3979 Chapter 5 [“Privacy and Confidentiality”]), and the REB may allow a waiver
3980 of consent under certain conditions (see Article 3.8 in Chapter 3 [“Free and
3981 Informed Consent”]).

3982 Secondary use of data identifiable as originating from Aboriginal participants
3983 or communities shall be subject to REB review to avoid harms ensuing from

3984 inadvertent identification of communities, potential misuse of cultural
3985 heritage, or misrepresentation of Indigenous knowledge when interpretation
3986 of data is no longer guided by community engagement. Any constraints
3987 imposed on use of the data in the original project should be noted if such
3988 information is available. Consistent with Article 5.6, the researcher should
3989 propose to the REB an appropriate strategy for securing agreement of the
3990 relevant individuals or group, or, if this is impossible or impracticable, there
3991 should be consultation with one or more organizations that are likely to
3992 represent the views and interests of the original participants.

3993 A common example of unauthorized secondary use of data that are
3994 identifiable as originating from a specific community is the practice of
3995 accessing traditional plant knowledge from the published literature to inform
3996 commercial development of products. In fields such as ethnobotany there is a
3997 significant amount of traditional knowledge that was published without the
3998 awareness or consent of the original knowledge holders. Researchers should
3999 seek culturally informed advice before use of such data to determine if harms
4000 may result and if benefit-sharing should be explored with the original source
4001 community.

4002 **Article 9.21** Researchers who propose research involving secondary use of human
4003 biological materials originating from Aboriginal peoples shall:

4004 (a) obtain research ethics board (REB) approval for the proposed research;
4005 and

4006 (b) engage the community from which the biological materials originated in
4007 accordance with any existing research agreement or the REB's direction;
4008 and

4009 (c) obtain consent of individuals from whom the biological materials
4010 originated unless:

4011 (i) an existing research agreement permits secondary use based on
4012 individual consent given at the time biological materials were
4013 initially collected; or

4014 (ii) the REB and the community agree that individual consent may be
4015 waived in accordance with Articles 12.5 or 12.6.

4016 **Application** Where the researcher can satisfy the REB that secondary use is consistent
4017 with an existing research agreement, the REB may require that the researcher
4018 engage the community from which the biological materials and associated
4019 identifiable information originate in accordance with the terms of the
4020 research agreement. New individual consent to secondary use is not required
4021 where the original consent authorized future use. Where secondary use has

4022 not been specified in the research agreement and authorized by the original
4023 individual consent, researchers shall engage the community from which the
4024 biological materials and identifiable information originate prior to initiating
4025 secondary use. Individual consent for the secondary use is required unless the
4026 REB and the community agree that Articles 12.4 or 12.5 applies.

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