



Government  
of Canada

Interagency Advisory Panel  
on Research Ethics

Ottawa, Canada  
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Gouvernement  
du Canada

Groupe consultatif interagences  
en éthique de la recherche

## Terms of Reference

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### Interagency Advisory Panel on Research Ethics

## GUIDING CONSORTIUM FOR THE DEVELOPMENT OF TCPS GUIDELINES FOR RESEARCH INVOLVING ABORIGINAL PEOPLE

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### BACKGROUND

In 1998, Canada's three federal granting agencies – the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council (NSERC), and the Social Sciences and Humanities Research Council (SSHRC) – adopted the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS) as a common statement of research ethics policy for the conduct of research involving humans in institutions funded by CIHR, NSERC or SSHRC. The TCPS has since been formally adopted in some 80+ university-based institutions across Canada. It is also used by some governmental departments and non-government organizations.

In 2001, the three federal granting agencies created the Interagency Advisory Panel on Research Ethics (PRE) as a body of interdisciplinary experts to provide independent advice on the development and further evolution of the TCPS. PRE is supported by an interagency Secretariat on Research Ethics (SRE).

Even before the establishment of PRE, it had become increasingly evident that the provisions of the TCPS for research involving Aboriginal Peoples (especially Section 6) warranted attention. New local, regional and international norms for research in Aboriginal communities have begun to emerge. For instance, in the five years since the adoption of the TCPS, a number of Aboriginal communities have enacted local research ethics protocols and standards. New and varied research initiatives involving Aboriginal Peoples, moreover, require more robust ethical guidance. Mindful of these needs, and in concert with the initial views of the three federal granting agencies and representatives from Aboriginal communities, PRE has designated the revision of Section 6 as a TCPS priority in its work plan. The Consortium is being convened to address this priority. [Statements describing each member's interest in this initiative may be added. See Appendix A]

## **OBJECTIVE**

This Consortium is created to collaborate with and provide guidance to the Interagency Advisory Panel on Research Ethics (PRE) in the development of guidelines for research involving Aboriginal Peoples. The process should draw on the evolution of research ethics in local Aboriginal communities and stimulate mutual and respectful exchange of knowledge between Aboriginal and non-Aboriginal research environments. PRE will recommend the resulting guidelines to CIHR, NSERC and SSHRC for incorporation into the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS).

## **PRINCIPLES**

Members of the Consortium agree to uphold the following principles in their work:

- conducting an open, inclusive, and participatory public process
- engaging Aboriginal Peoples and the research community
- drawing on diverse disciplines and cultural approaches
- fostering constructive collaboration and partnerships
- building on international, national and local models, especially those respectful of Aboriginal knowledge, methodologies and communities.

## **MEMBERSHIP**

The Consortium membership shall be representative of the diversity of the research community and Aboriginal Peoples. Membership will be for three years, and shall be composed of

- 5 members from the core Aboriginal organizations listed below
- 3 members from the three federal granting agencies (CIHR, SSHRC, NSERC)
- 1 member from the Interagency Advisory Panel on Research Ethics
- 1 or more Elders

The founding members of the Consortium include PRE, the Assembly of First Nations (AFN), Métis National Council (MNC), Inuit Tapiriit Kanatami (ITK), Native Women's Association of Canada (NWAC), Congress of Aboriginal Peoples (CAP), and the three federal granting agencies. The full complement of members will be determined by the founding members at the first meeting of the Consortium.

**Observers & Ex Officio:** The Consortium may invite observers and special guests to participate in its meetings. A policy on *ex officio* members may be developed.

- 3-5 members non-voting, *ex officio* from the federal government (e.g., Health Canada, Justice, to be determined)
- 1 or 2 representatives of non-government organizations – to be determined

**Chair:** The representative of the Interagency Advisory Panel on Research Ethics (PRE) will serve as Chair of the Consortium.

## **DECISION MAKING PROCESS**

*Consensus & Quorum:* Unless the Consortium members decide otherwise, decisions will generally be achieved by consensus. Quorum for the Consortium will consist of representation of three (3) Aboriginal organizations, two (2) federal granting agencies, and the PRE representative.

*TCPS Policy Process:* Through the Consortium process, PRE and its collaborators will strive towards common ground on TCPS policy issues, and respect one another's views in doing so. Consensus views of the Consortium will be reflected in PRE's draft and final recommendations to the Agencies. Deliberative analysis and debate will often, but perhaps not always, yield consensus. Respectful and meaningful engagement of Aboriginal Peoples further means that PRE will honour the integrity of their views -- whether they converge, parallel, or diverge from those of PRE or others. If their views or positions cannot be adequately accommodated in PRE's TCPS recommendations on a particular issue, then either the recommendations will be deferred or the positions and their underlying rationales will be portrayed accurately as dissenting positions or alternative policy options. Through such participation, the views and values of Aboriginal Peoples will advance sustainable human research ethics guidelines for the TCPS.

## **MEETINGS & CALENDAR**

Members of the Consortium will strive to conclude this initiative within three years on the basis of an agreed work plan. The Consortium will normally meet at least twice annually.

## **ROLES & RESPONSIBILITIES**

The roles, responsibilities and functions of the Consortium members include the following:

1. to facilitate the engagement of member communities in this initiative;
2. to foster effective working relationships and collaboration between the federal granting agencies, Aboriginal communities, PRE, government departments and other organizations relevant to research involving Aboriginal Peoples;
3. to identify human research ethics issues important to Aboriginal Peoples;
4. to offer commentary and advice to PRE on a range of important matters for this initiative, such as the work plan for the project, membership of working groups, research requirements, selected working documents, the mode(s) and timing of consultation, etc.;
5. to comment and advise on draft policy recommendations;
6. to make recommendations to PRE on the ethics of research involving Aboriginal Peoples and communities. Final adoption of the PRE's recommendations for integration of revised guidelines in the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS)* remains the prerogative of CIHR, NSERC and SSHRC through their respective governing councils.

PRE will convene a Technical Advisory Committee on Aboriginal Research (PRE-TACAR) made up amongst others of Aboriginal and non-Aboriginal persons involved in Aboriginal research to advise and otherwise assist in researching and analyzing issues and drafting policy documents for consideration by PRE and the Consortium. Joint meetings of PRE-TACAR members and the Consortium may be scheduled as required.

An interagency staff working group composed of staff from the Secretariat on Research Ethics (SRE), the three federal granting agencies, and Aboriginal organizations will be convened to support implementation of the work plan as required.

Subcommittees of the Consortium may be established as required.

## **REPORTING**

Each member of the Consortium shall liaise with his or her respective corporate entity, providing progress reports and soliciting feedback. The Consortium will report on a regular basis to PRE.

## **SECRETARIAT**

Operational support of the Consortium will be provided by the Interagency Secretariat on Research Ethics (SRE).

## **CONTRIBUTIONS & COSTS**

- Each member organization will cover the costs of its own participation in the Consortium unless agreed otherwise.
- The SRE will develop a budget, consistent with the work plan, for implementation of this initiative.
- Where appropriate, memorandums of understanding will be developed to detail collaborative contributions and agreements.

## **RELATED DOCUMENTS**

This document should be read in conjunction with the companion documents noted below, which outline the complementary roles and responsibilities involved in this PRE initiative.

- Member Statements (To be determined)
- PRE Technical Advisory Committee on Aboriginal Research (PRE-TACAR) Terms of Reference
- Collaborative Development of Ethical Guidelines for Research Involving Aboriginal Peoples

# Collaborative Development of Ethical Guidelines for Research Involving Aboriginal Peoples

