

UQAT Seminar on  
Ethics of Research, Sept. 20,2011

## Enabling Respectful Relationships: The policy approach of TCPS 2, Chapter 9 .

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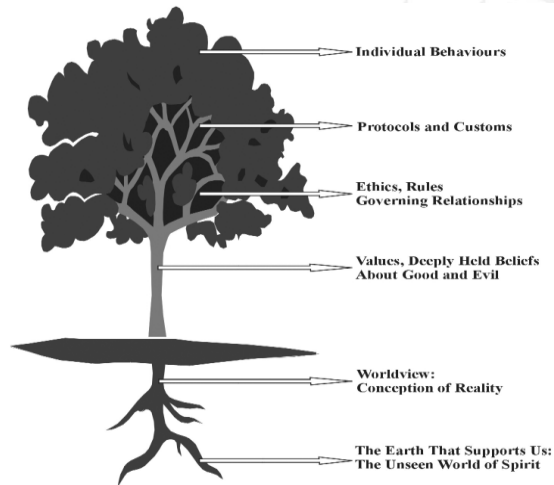
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## Defining “Ethics”

- Rules of behaviour
- Willie Ermine (Cree): Ethics is how we treat one another
- In a close-knit community ethical rules may be unwritten, unspoken
- In professional communities (lawyers, doctors) they are written as a code of conduct
- Codes of research ethics date from Nuremburg

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## Native Ethics



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## The TCPS: Joint policy adopted 1998 Updated: TCPS2 December 2010

- Canadian Institutes of Health Research (CIHR)
- Natural Sciences and Engineering Research Council (NSERC)
- Social Sciences and Humanities Research Council (SSHRC)

Binding on: All research institutions and researchers eligible to receive funding from the three research Agencies

Adopted or used by other agencies and some government departments for guidance

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## TCPS Ethics Framework: Core Principles

- Respect for Human Dignity expressed in three core principles:
  - Respect for persons
  - Concern for welfare
  - Justice
- Application of the Ethics framework requires clarification of application in First Nations, Inuit and Métis contexts (Chapter 9)

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## Principle: Respect for Persons

- Recognizes the inherent value of human beings and the respect and consideration that they are due
- Incorporates the dual moral obligations to respect personal choice (autonomy) and to protect those with developing, impaired, or diminished autonomy, i.e. children, disabled or ill persons.

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## Principle: Concern for Welfare

- Protecting the welfare of participants in view of any foreseeable risks associated with the research
- Welfare refers to all aspects of a person's well-being including: physical, mental and spiritual health, physical, economic and social/cultural dimensions

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## Principle: Justice

- The obligation to treat people fairly and equitably
- Entails treating all people with equal respect and concern
- Equity requires distributing the benefits and burdens of research participation in such a way that no part of the population is unduly burdened by the harms of research or denied the benefits of the knowledge generated from it

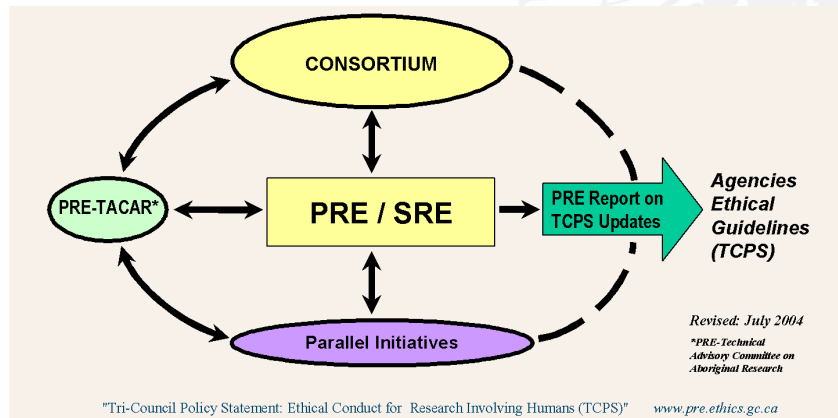
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## The Challenges of Writing Policy Affecting Aboriginal People

- Diversity of First Nations, Inuit and Metis peoples, urban and rural, traditional and acculturated
- Distrust resulting from past experience
- Multiple constituencies involved in research
- Language differences discussing ethics
- Rapidly changing environment of research
- Contested interpretation of rights

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## Collaborating to Find a Balance



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## Collaborating to Find a Balance

- For Chapter 9, PRE sought input from:
  - Consortium including 5 national Aboriginal organizations, research agencies, federal ministries
  - Advisory committee of academics doing research with Aboriginal communities
  - Other organizations that had developed similar policies
- PRE integrated CIHR's Guidelines on Health Research Involving Aboriginal Peoples

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## An Ongoing Process

- Reclaiming lands and territory
- Asserting rights to survive and thrive as Peoples
- Reclaiming the territory of the mind
  - Renewal of language and culture
  - Education
  - Recognition of oral history – Delgamuukw
  - “Researching ourselves to life”
- Royal Commission on Aboriginal Peoples
- TCPS2 – Chapter 9 → → →

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## Chapter 9: Research Involving First Nations, Inuit and Métis Peoples in Canada

### A dedicated chapter in an integrated document

#### Key provisions

- where the research is likely to affect a First Nations, Inuit or Métis community or communities to which potential participants belong, researchers **shall** seek engagement with the relevant community
- Nature and extent of community engagement in a project to be determined jointly
- Engagement should be appropriate to community characteristics, nature of research

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## Why “Community Engagement” ?

- An inclusive term that covers a broad range of relationships
- Engagement does not impose restrictions on community processes
- Enables parallel, collaborative processes between community and research institution

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## Types of Community

### Territorial community

- Has a governance structure, exercises jurisdiction

*Example:* members of a First Nation

### Organizational community

- Has a mandate, membership and formal leadership

*Example:* tribal council, service organization

### Community of Interest

- Fluid boundaries, shared interests

*Example:* network to conserve an Aboriginal language

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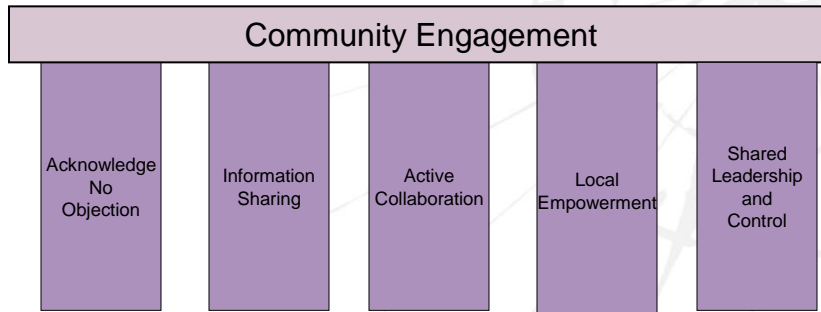
## Forms of Engagement



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## Levels of Engagement



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## Institutional Review Requirements

- Review required at institutional level **and** by community REB or other similar body, if it exists
- Researchers shall advise institutional research ethics board how they have engaged or propose to engage the community

**OR**

Present a rationale why exception to the requirement is appropriate

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## Research Agreements

- Used when a community has formally engaged with a researcher through a designated representative
- Clarifies and confirms mutual expectations and commitments, including research ethics review
- Precedes participant recruitment and data collection
- Consent of individuals required in addition to community agreement

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## Examples of Issues that Need Advance Consideration (1)

- How community codes fit with TCPS requirements
- Privacy of individual participants in small communities
- Processes for review of findings prior to publication
- Sharing benefits of research
- Recognizing contribution of individuals
- Unique role of Elders

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## Examples of Issues that Need Advance Consideration (2)

- Intellectual property, i.e. ownership and control of research data, reports and publications
- Secondary use of data beyond the specific purpose of the research

**TCPS2 , Chapter 9 includes 22 specific articles, with examples, to enable communities and researchers to engage in respectful relationships, for mutual benefit.**

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## Limits of the TCPS

- This is a policy statement on ethical conduct **involving humans**, that is, persons who provide information or biological materials
- TCPS does not cover research on the environment or wildlife, although other policies may apply
- TCPS does not set the rules for source funding
- TCPS is a guidance document for those eligible to receive Agency funding. Implementation (and dealing with violations) is the responsibility of the institution or organization which wishes to maintain eligibility for funding.

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## Additional Resources

- TCPS2 available at: [www.pre.ethics.gc.ca](http://www.pre.ethics.gc.ca) ; [www.ger.ethique.gc.ca](http://www.ger.ethique.gc.ca)
- Castellano, Marlene Brant : « Ethics of Aboriginal Research » in *Journal of Aboriginal Health*, 1(1), 98-114 . Available at: <http://www.naho.ca/journal/2004/01/08/ethics-of-aboriginal-research/>
- Marlene Brant and Jeff Reading: "Policy Writing as Dialogue: Drafting an Aboriginal Chapter for Canada's Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans" in *International Indigenous Policy Journal*, Vol. 1, Issue 2. Available at <<http://ir.lib.uwo.ca/iipj/vol1/iss2>