

# **Assessing the Impact of New Ethical Guidelines on Métis Specific Health Research**

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# Old Ethical Guidelines

- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada. (1998 with amendments 2000, 2002, 2005) *Tri-council Policy Statement: Ethical Conduct for Research Involving Humans*. Found on the web: October 28, 2009.

[http://pre.ethics.gc.ca/policy-politique/tcps-eptc/docs/TCPS%20October%202005\\_E.pdf](http://pre.ethics.gc.ca/policy-politique/tcps-eptc/docs/TCPS%20October%202005_E.pdf)

# New Ethical Guidelines I

- Canadian Institutes of Health Research (CIHR). (2008 a). *CIHR Guidelines for Health Research Involving Aboriginal Communities*. Found on the web: December, 2008. [http://www.cihr-irsc.gc.ca/e/documents/ethics\\_aboriginal\\_guidelines\\_metis\\_e.pdf](http://www.cihr-irsc.gc.ca/e/documents/ethics_aboriginal_guidelines_metis_e.pdf)

# New Ethical Guidelines II

- Interagency Advisory Panel on Research Ethics. (December 2008). Draft 2<sup>nd</sup> Edition of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. Found on the web: October 29, 2009.  
<http://pre.ethics.gc.ca/policy-politique/docs/TCPS-Draft2-eng.pdf>.

# Assessing the Possible Effects of Guidelines on Métis *Communities*

- Difficult to do in the abstract, and as the guidelines are new (and draft)
- But the CIHR guidelines are all ready having an impact, and similar understandings of community are operationalised in both.
- “Community” is undefined but central

# Concern: two key flaws

- Assumes (or at least selects for) a level of infrastructure that many (maybe even most) Métis communities simply do not have
- Assumes a 'landedness' to community (like specific First Nations or Métis Settlements) which, though conceptually convenient, fails to account for the formation and survival of communities not so easily recognized according to such criteria

# From Good Beginnings

Decolonization of research

via

Indigenous Methodologies

&

Development of new ethical guidelines with considerable power.

so

All the more reason to get it right.

# Lack of Métis Research

- Medline database (1992 – 2001) - 254 articles related to Aboriginal health in Canada (Young, 2003). Only 2 of the papers from this search provided data about Métis people.
- Social science databases (1995 – 2005) resulted in 96 articles on Aboriginal health issues of which only 14% had Métis representation (Wilson and Young, 2008).
- CIHR funding for Métis health research ranging between 2-8%

# Elusive Partners - Lack of Infrastructure

- Absence of community healthcare structures and
- Absence of other types of institutional partners with whom to partner
- Absence of human capacity within the community to collaborate with researchers
- All these have effected research to date – and now Community is very nearly required by the guidelines

# Aboriginal Communities

- Most easily recognizable in a rural/reserve context (but this is a quickly changing reality for most Aboriginal people)
  - One community
  - One place/local
- But such community formations are relatively new
- And community was always complicated for Métis

# Métis Communities

- Mobile
- Complexly interwoven in place with other communities
- Complexly interwoven with the institutions of other communities
- Complexly multi-local – indeed the Historic Metis Nation stretched across the breadth of north central America

# New Métis Communities

- Often Urban – often linked and overlapping with the Urban Aboriginal Communities
- Linked and overlapping institutions – including those of Traditional Territory holders
- Often in complex and fluid political contexts

# An unfortunate (and now corrected) example in the 2nd draft of the Tri- Council Policy Statement

- Article 9.2 (2008, 95-96) : In research proposals involving one or more Aboriginal communities or a significant number of Aboriginal participants, researchers shall inform the research ethics board of how they have engaged or intend to engage the community in approving, advising on or managing the project. The nature and extent of community engagement should be appropriate to the type of community and proportionate to the level of Aboriginal involvement in the research.

# The Example

- *Examples of Aboriginal involvement:* “Research involving Aboriginal people who comprise a sizable proportion of the study or community and where Aboriginal-specific conclusions are intended. Example: a comparative study of access to public housing in Prince Albert, Saskatchewan.
- *Examples of proportionate community engagement*  
The tribal council representing local First Nation communities may partner with the Prince Albert city council to sponsor, implement and use the results of the housing study.

# The Problem

- Prince Albert has an extremely high proportion of Métis in the city, and the city serves a number of rural and peri-urban Métis communities; the 2006 Canada Census data indicates that just under half of all Aboriginal people in the city (5835 of 12140 persons) and census agglomeration (6680 of 13570 persons) identified themselves a Métis (as a single response) (Statistics Canada, 2008).

# Conclusion: Community Matters

- In terms of effective research / ethical research
- And it must be subtly applied – especially and urgently in the context of Métis research
- These new guidelines matter, and their impact - *in practice* - must be monitored ....