

JERHRE NOTES

Skills for Solving Ethical Problems in Human Research

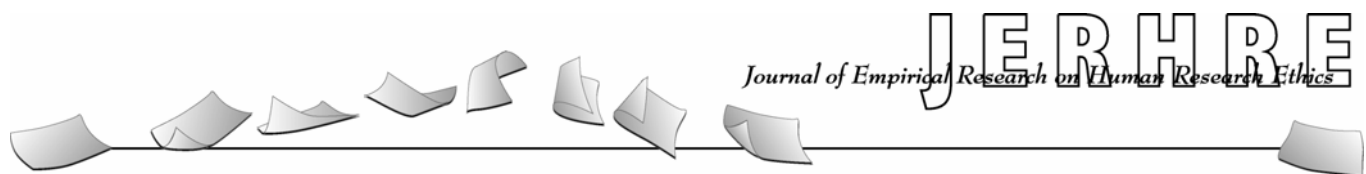
RECONCILING ETHICS REVIEW AND ABORIGINAL COMMUNITY VALUES

Indigenous researchers have identified key issues (e.g., community consent, participatory models of research, protection of traditional knowledge, opportunities for community interpretation of data) of relevance to them, but often ignored by most research-ethics committees (RECs). To accommodate both interests, *relevant cultural expertise* is needed and may be attained via: (a) a consultant competent in local knowledge, traditions and values; (b) education of external REC members; (c) Aboriginal community representation and membership on external RECs, or (d) development of Aboriginal community advisory committees or regional research ethics reviews.

Relevant cultural expertise for RECs includes understanding pertinent local knowledge; participatory and consensus-oriented decision processes; history of research relationships with Aboriginal communities; and willingness to defer to community knowledge to have culturally safe research. Issues such as risk assessment often require intimate knowledge of the community in question that an external REC may not possess. An REC lacking this expertise may be able to engage community representatives who are capable and willing to conduct a joint evaluation of the research, or by seeking the services of an Aboriginal consultant on cultural and ethical issues. Parallel consultation and education may be useful in building capacity in research ethics review for both Aboriginal communities and policy makers.

A mandatory formal agreement concerning data ownership, interpretation/analysis and publication, with specific mechanisms for managing conflicting interpretations or inappropriate use of data should be entered into between the community authority and the investigators at an early phase of the relationship. Both parties should agree in advance on their roles and responsibilities, desired outcomes, measures of validity, control of the use of data, funding and channels to disseminate findings. Formal agreement should protect both researchers and participating communities from unreasonable restrictions on access to data or the right to publish findings. One possible mechanism for resolving disputes over dissemination is advance agreement that publication will include dissenting views of researchers and/or community, if the partners cannot agree on the interpretation.

Kathleen Cranley Glass & Joseph Kaufert (2007). Research ethics review and Aboriginal community values: Can the two be reconciled? *Journal of Empirical Research on Human Research Ethics*, 2(2), 25-40.



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