

## Chapter XIV

# Ethics Review Concerns of Canada's Distance Researchers

**Patrick J. Fahy**  
*Athabasca University, Canada*

### ABSTRACT

*Ethics review of research involving humans is intended to protect human dignity by balancing harms and benefits. The foci and methods used in reviews vary nationally, but tend, as in Canada, to address core principles including free and informed consent, privacy and confidentiality, inclusiveness and fairness, and the rights of dependent subjects. Under examination in relation to the policy that governs research ethics in Canada, the Tri-Council Policy Statement (TCPS, 2005), these principles admit numerous exceptions, a fact that, as shown by a study reported here, is better understood by those actually engaged in research than those who are not. The implications of these findings, and the specific priorities of non-Canadian researchers (especially those in developing nations), are described and discussed.*

### BACKGROUND

The global increase in online and distance programming has resulted in widespread interest on the part of researchers in exploring and analyzing distance learning processes and outcomes (Bucharest Declaration, 2004; Mishra, 1998; *Tri-council Policy Statement* [TCPS], 2005). At the same time, granting agencies almost globally have increased their scrutiny of the ethics of research involving humans, especially in universities and

other centres where public funding is typically used by researchers.

While distance practitioners internationally appear almost universally to support research standards (Gordon & Sork, 2001), in the view of some the effect of increased scrutiny by some ethics review has sometimes been deleterious, constraining unnecessarily the scope of inquiry, inhibiting or limiting innovative or unconventional methods, lengthening and complicating the process of gaining research approvals, whether

externally funded or not, and, in some particularly unfortunate cases, resulting in the outright cancellation of projects (“Complexity of the IRB process,” 2005; Rourke, Anderson, Garrison, & Archer, 2001; Savulescu, Chalmers, & Blunt, 1996). The impact on distance researchers has been particularly severe, as distance research almost always involves human subjects, and often entails the collection and analysis of personal data.

In Canada, the *Tri-council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS, 2005) is the federal government’s statement on research ethics principles applicable to institutions receiving federal funding (Medical Research Council of Canada, 2005). The TCPS articulates the standards that Research Ethics Boards (REBs), responsible for applying the TCPS institutionally, must enforce. The purpose of the TCPS is to assure ethical treatment of human research subjects in Canada. While there is no debate about the worth of this objective, there have been several conflicts since the appearance of the TCPS in 1998 over how this goal might best be achieved. Specifically, there is lively debate about whether the current policy guarantees appropriate freedom for researchers, especially those in the social sciences and humanities, whose work is typically minimal- or no-risk.

The nature of core ethical principles contained in the TCPS, their interpretations, their similarities to and differences from global standards and concerns, and some of the implications of these for distance research are discussed in the following.

## **IDENTIFYING CORE ETHICAL PRINCIPLES**

The objections of social sciences and humanities researchers to aspects of the Canada’s TCPS, and to some practices of REBs in implementing it, do not question the importance of ethical treatment of subjects. There are two issues: how

distance research, as a form of social science inquiry, may adhere to high ethical standards, given the special circumstances under which that research is often conducted; and how the approval process for distance research might be revised—made “proportionate”—to the low levels of risk that usually accompany these proposals (TCPS, 2005, p. 1.7).

The debate about core ethical principles and proportionate review of proposals is not new. Globally, ethics in human subjects’ research has been the subject of increasingly heated debate for some time, in North America even appearing in the popular press. Beck and Kaufman (1994) some time ago identified various ethical “pitfalls” that could entrap researchers; in 2002, Begley (2002) described, in *The Wall Street Journal*, a growing “rift” between researchers and ethicists; more recently, others (Dohy, 2004; Elliott & Lemmens, 2005; Lemonick & Goldstein, 2002; Munro, 2004) have publicly raised questions about doubtful practices such as paid ethics review in clinical trials, while bloggers have debated the impartiality of online product reviews (Lasica, 2005).

To create a common ethics framework for researchers and those responsible for reviewing and approving research proposals, policies such as the TCPS present principles that researchers must respect and REBs enforce. Key principles contained in the TCPS include:

- Respect for human dignity
- Free and informed consent
- Privacy and confidentiality
- Inclusiveness and justice
- Balancing of harms and benefits
- The status of “subjects” in clinical and nonclinical research
- The role and composition of REBs

Human dignity. Interest in this principle arises chiefly from the emergence of programs of systematic, industry-funded medical research (Evans & Jakupiec, 1996, p. 72), and from egregious

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