# Highlights of the Forthcoming Report "Giving Voice to the Spectrum" from PRE's Social Sciences and Humanities Research Ethics Special Working Committee (SSHWC)

Interagency Advisory Panel on Research Ethics (PRE)

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# Introduction

In May 2003, the Interagency Advisory Panel on Research Ethics (PRE) struck a Social Sciences and Humanities Research Ethics Special Working Committee (SSHWC), to examine issues in the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS) related to research in the humanities and social sciences. SSHWC was mandated to assist PRE by providing it with advice and recommendations on strategic approaches for addressing priority issues in social sciences and humanities research ethics for the TCPS<sup>1</sup>.

PRE now wishes to update the research community on the initiative. PRE is pleased to report that SSHWC has completed the first stage of its work, which will be shortly released in the form a document, "Giving Voice to the Spectrum." The report is based largely on consultations undertaken in the summer and autumn of 2003. The following provides an interim summary of the background, process and major themes identified in the report.

Before turning to the summary, it should also be noted that SSHWC and PRE have begun to address the early results of this ongoing initiative. SSHWC is currently developing a work plan for addressing the major issues identified in the report. To facilitate the undertaking of the work plan, PRE has (a) extended the mandate of the SSHWC until August 2005; (b) has revised SSHWC's terms of reference; and (c) has expanded SSHWC membership to include a member who is active in the field of creative and performance-based research. These changes should facilitate the development of SSHWC's advice and recommendations to PRE on social sciences and humanities (SS&H) priority areas in need of revision in the TCPS.

The themes in the forthcoming report are the results of SSHWC consultation, which at this early stage of the process provide initial policy options for consideration by, but may not reflect the policy recommendations of, PRE. They give voice to the spectrum of issues and concerns that will inform SSHWC's work plan and its future recommendations to PRE for strengthening the TCPS. Based on such policy options, PRE will develop final recommendations to the three granting agencies -- the Canadian Institutes for Health Research (CIHR), the Natural Sciences and Engineering Research Council (NSERC) and the Social Sciences and Humanities Research Council (SSHRC). PRE is confident that the report, work plan, ongoing advice and recommendations from SSHWC will help make the TCPS more relevant for the broad range of research conducted by the social sciences, humanities and research community at large.

# **SSHWC** Activities and Findings

Consistent with PRE's first principles for the evolution of the TCPS -- transparency, community engagement and consultation -- SSHWC undertook diverse information gathering strategies, including a national solicitation of commentary from members of Canada's social science and humanities research communities regarding their experiences with and reaction to the TCPS and its implementation<sup>2</sup>.

<sup>&</sup>lt;sup>1</sup> http://pre.ethics.gc.ca/english/workgroups/sshwc.cfm

<sup>&</sup>lt;sup>2</sup> A copy of the formal solicitation is available

In an effort to ensure contributions from as broad a spectrum of Canada's social sciences and humanities research communities as possible, members of SSHWC did the following:

(1) analyzed solicited and unsolicited submissions that were received by the Secretariat on Research Ethics prior to the inception of SSHWC, and which arose after members of the Panel and the Secretariat attended scholarly gatherings and encouraged such submissions in 2002 and early 2003;

(2) attended scholarly conferences in the summer of 2003 where the SSHWC initiative was discussed and further written submissions were encouraged;

(3) initiated one or more consultation sessions in SSHWC members respective university communities with REBs, academic departments, research institutes and/or individuals on an open invitation basis; and

(4) Engaged in a national consultation in which the SSHWC encouraged commentary from the community both passively and actively (actively, by inviting written submissions from disciplinary and trans-disciplinary associations and organizations, university administrators, VPs-Research, Deans and Heads of Departments, and ethics list-serves; and passively, by inviting those who visited PRE's website to contribute.)

Members of Canada's social science and humanities research communities responded by sending their stories and concerns. Fifty-seven different submissions comprising hundreds of pages of commentary and suggestions arrived from individuals, REBs, disciplinary associations, trans-disciplinary organizations and institutes representing at least seventeen different disciplines. Face-to-face consultations supplemented the written record.

While these sources leave SSHWC confident in its conclusions and recommendations with respect to the social sciences, the relatively limited number of formal submissions coming from persons in the humanities may mean the report does not reflect the full range of concerns experienced by researchers in the humanities. This limitation will need to be addressed in SSHWC's work plan.

# Salient Themes

The following is a thematic synopsis of priorities and recommendations contained in SSHWC's report. These are all matters that SSHWC believes PRE should consider as it takes the *Tri-Council Policy Statement* to the next stage of its evolution. SSHWC has agreed to move forward with more detailed planning based on these themes.

- The TCPS needs to be more inclusive of the variety of different research methods used in the social sciences and the humanities.
- The submissions to SSHWC indicate alternative approaches to revising the TCPS. The report explores the strengths and weaknesses of each approach and concludes that

http://pre.ethics.gc.ca/english/public participation/call for comments/evolving tcps.cfm

both editorial and substantive revisions are necessary to maintain the value of the TCPS in light of the diversity of research approaches that characterize the social sciences and humanities. These changes also implicate the processes of ethics review in a manner that is sensitive to and appreciates these characteristics/differences. The question that remains is what degree of separation is warranted between review processes that govern biomedical/experimental versus non-experimental/ inductive/field-based approaches to research.

- The TCPS should reconsider the types of research that require review and approval by Research Ethics Boards (REBs) and be more clear, taking into account a clearer definition of minimal risk. In some scholarly domains, default assumptions regarding risk should be reconsidered, with the bio-medically appropriate concept of "minimal risk" being reformulated as "identifiable harm," with the attendant need for clarification of which prospective "harms" in the social sciences and humanities might warrant REB attention.
- A better balance is required between respect for the rights of research participants and the need for free and open inquiry. The balance should be commensurate with the lower magnitude of prospective harm that characterizes most social science and humanities research. SSHWC suggests this might be achieved most effectively by a shift in onus where, in order to require changes to a research proposal, an REB would be obliged to explain what identifiable harm has not been addressed, and how their proposed solution will ameliorate the problem.
- Informed consent is a universally important component of respect for the autonomy of research participants, but the approach to consent in the present TCPS is narrowly conceived and does not fit many modes of inquiry in the social sciences and humanities. SSHWC recommends the idea of consent (and default expectations about the way it is obtained) be considered further, with a view to making the TCPS more inclusive and better reflective of the diversity of ethical relationships that exist between researchers and participants.
- Anonymity and confidentiality both need to be explored further to ensure that a variety of contexts are open to scholarly inquiry -- taking into account the fact that many social problems cannot be investigated without a guarantee of confidentiality while, on the other hand, in some projects participants are willing to be or want to be identified, and failing to do so would be a sign of disrespect.
- The TCPS needs clear guidelines about the conditions under which Research Ethics Boards judge the scholarly merit of research proposals. When scholarly merit is adjudicated as part of the REB process, there should be a better mechanism for carrying out such adjudication, given the necessarily limited range of disciplinary and/or methodological expertise of the scholars who are members of the REB.
- A single-project approach to REB review is problematic to the extent that much social science and humanities research is less "project" and more "programme" based. SSHWC recommends that PRE consider different approaches to ethics review that would allow REB blanket approval of programmes of research based on the overall

ethics strategy of the researcher (or team of researchers) within specified parameters. A programmatic approach would clarify issues such as default procedures of consent and protection of privacy, retention of data, and secondary analysis of data.

- PRE should consider exemptions from review for social science and humanities research that involves standard practice in the discipline involved, particularly where the research participant is not a "human subject," there is no identifiable harm, and where the provision of confidentiality ensures participants cannot be identified. REB resources should be focused more on "special" cases that pose unique challenges and warrant extended scrutiny which, in the social sciences and humanities, are the exception rather than the rule.
- There is wide divergence in practices across institutions with respect to research undertaken by students in course-based projects. SSHWC recommends that the PRE offer standardized guidelines that recognize the importance of these supervised skills-appropriate opportunities for the development of research expertise and ethical sensibility.
- Research that crosses international and other jurisdictional boundaries requires further consideration with respect to jurisdiction, different cultural expectations, and other complexities that arise in inter-societal, inter-cultural research.
- Members of SSHWC also are concerned about the absence of any significant documentation regarding how the implementation of the TCPS might have been experienced by more creation- and/or performance-based researchers in the humanities (e.g., musicians; visual artists; performance artists).<sup>3</sup>
- The SSHWC's overarching recommendation is that PRE now move to the next stage -- specific revision of the TCPS along the lines suggested in the report.

<sup>&</sup>lt;sup>3</sup> As noted above, PRE has responded by adding a researcher with creation/performance based expertise to SSHWC for its continued work.

# A Way Forward: Next Steps

Based on the submissions, SSHWC had identified a specific list of issues that will be addressed in the development of the work plan. After PRE approves the work plan, SSHWC will proceed to implement it with a focus on developing potential changes for the TCPS for PRE's consideration. SSHWC will use a variety of approaches to develop its policy recommendations, including consultations with experts, reviewing policies from other jurisdictions, literature review and synthesis, and engaging various stakeholders.

## Membership of the PRE Social Sciences and Humanities Research Ethics Special Working Committee

Members

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