Giving Voice to the Spectrum

**Report of the
Social Sciences and Humanities Research
Ethics Special Working Committee**

to the

**Interagency Advisory Panel on Research
Ethics**

June 2004

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Executive Summary

In May 2003 the Interagency Advisory Panel on Research Ethics (PRE) struck the Social Sciences and Humanities Research Ethics Special Working Committee (SSHWC) [1] 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. The Committeeundertook to identify and prioritize issues, and to recommend action to address these issues.

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.[2]

The following is a thematic synopsis of priorities and recommendations contained in the report.[3] These are all matters that the Advisory Panel should consider as it takes the *Tri-Council Policy Statement* to the next stage of its evolution. We recommend they form the basis of further activity by SSHWC if PRE decides to extend its mandate.

- The TCPS needs to cover a greater variety of the research methods used in the social sciences and the humanities.

- The report outlines four alternative approaches to revising the TCPS. SSHWC rejected two of these; the remaining two maintain our interest. The two options SSHWC favours involve providing more information regarding the diversity of research approaches that characterize the social sciences and humanities *and* follow through to adapt 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 respective viability of the two options discussed in the report will become more apparent if PRE gives SSHWC a mandate to pursue its proposed work.

- The sorts of research that require review and approval by Research Ethics Boards (REBs) should be reconsidered and be more clearly specified, taking into account

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[1] A list of committee members and their affiliations appears in Appendix A.
[2] A copy of the formal solicitation appears in Appendix B.
[3] A complete and detailed list of priority recommendations, which the Committee refers to as "Implications for Change," appears in Appendix C. The rationale for these recommendations appears in the main body of the report.

a clearer definition of minimal risk. In some scholarly domains, default assumptions regarding risk should be reconsidered, with the biomedically 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 subjects and the need for free and open inquiry. That 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 better include and reflect the diversity of ethical relationships between researchers and participants.

- Anonymity and confidentiality 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, as well as, on the other hand, that in some projects participants are willing to be or want to be identified, and that 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 "program" based. SSHWC recommends PRE consider different approaches to ethics review that would allow REB blanket approval of programs 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 in these situations: where the research participant is not a "human subject," where

there is no identifiable harm, and where the provision of confidentiality ensures that participants cannot be identified. REB resources should be focused more on "special" cases that pose unique challenges and warrant extended scrutiny. (In the social sciences and humanities, these 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 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 intersocietal, intercultural research.

- Members of SSHWC also are concerned about the near-absence of documentation regarding how creation- and/or performance-based researchers in the humanities (such as musicians, visual artists and performance artists) might have experienced the implementation of the TCPS. If the mandate of SSHWC is renewed for a second phase, we ask PRE to consider adding a researcher with that expertise to the committee.

- SSHWC's overarching recommendation is that PRE now move to the next stage—specific revision of the TCPS along the lines suggested in our report—and consider an extension of mandate to allow for that work to be accomplished.

I. Introduction

Mandate

The Social Sciences and Humanities Research Ethics Special Working Committee (SSHWC) is pleased to submit its report to the Interagency Advisory Panel on Research Ethics (PRE) regarding our recommendations for future development of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (the TCPS). Our mandate is to "provide advice and recommendations to PRE on (a) priorities and (b) methods and strategies for coherently addressing priority ethical issues in social sciences and humanities research involving human participants."[4] This reflects the granting agencies' intention that the TCPS should evolve on the basis of changing sensibilities and experience with its implementation. This report describes the results of SSHWC's first six months of work (May–November 2003).

Methods

PRE's "first principles of the evolution of the TCPS" assert its commitment to "transparency, community engagement and consultation." We endeavoured to follow those dicta in a national solicitation of commentary from the country's social sciences and humanities communities about their experience with the first five years of the TCPS.[5] To ensure contributions from as broad a spectrum of Canada's social sciences and humanities research communities as possible, SSHWC did the following:

(1) analyzed submissions (solicited and unsolicited) that the Secretariat on Research Ethics (SRE) received prior to the inception of SSHWC, and that 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 consultations in our respective university communities with REBs, academic departments, research institutes and individuals on an open invitation basis; and

(4) engaged in a national consultation, in which SSHWC encouraged electronic submissions both passively and actively: actively by sending e-mail messages to an extensive list of disciplinary and trans-disciplinary associations and organizations, university administrators (including vice-presidents, research; deans and heads of departments), and disciplinary and ethics e-mail forums; and passively by providing a Web site at which anyone who arrived by encouragement, curiosity or serendipity could contribute.[6]

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[4] http://pre.ethics.gc.ca/english/publicparticipation/callforcomments/evolvingtcps.cfm
[5] A copy of the formal solicitation may be seen in Appendix B.
[6] http://pre.ethics.gc.ca/english/publicparticipation/callforcomments/evolvingtcps.cfm

Members of Canada's social science and humanities research communities responded by sending their stories and concerns. Fifty-seven submissions, comprising hundreds of pages of commentary and suggestions, arrived from individuals, REBs, disciplinary associations, trans-disciplinary organizations and institutes representing at least 17 different disciplines. Face-to-face consultations supplemented the written record.

While these sources leave us confident in our conclusions and recommendations with respect to the social sciences, we are more cautious in claiming that we understand the full range of problems that researchers in the humanities experience. Notwithstanding that several members of SSHWC represent "humanities" disciplines/research areas, the number of formal submissions from persons in the humanities was limited.

To the extent that many of the issues raised by social science researchers may be generalizable to the humanities—and one might argue that when humanities' pursuits involve human participants they effectively become "social science"—the limitation poses no problem. However, humanities disciplines that are now only beginning to come under REB jurisdiction—including creation- and/or performance-based research, which have strong traditions of resistance to control, which they perceive as "censorship"—are more problematic. Persons engaged in these areas may not yet see the TCPS as "relevant" and/or may not yet have experience dealing with REBs. Therefore, any problems that might exist remain invisible. Whatever the case, we acknowledge this limitation to our work.[7]

II. Social Sciences and Humanities at a Crossroads

One Size Does Not Fit All

If there is a fundamental problem we can identify, it is that the granting agencies' desire to create a regulatory structure to deal with the stereotypical clinical trial has resulted in a document and set of structures that assume different modes of research involving different relationships and different concerns than most social science and humanities researchers seek and encounter. Stated simply, the TCPS does not "speak" to their experience, leaving REBs that may lack appropriate breadth of expertise free to impose default assumptions that threaten free inquiry for no ethical gain. The further one's research gets from the paradigmatic/positivist/experimentalist assumptions and understandings that permeate the TCPS, the more ill fitting the TCPS's application becomes. As this implies, although the deleterious effects of the TCPS have been felt across the social sciences and humanities, it is the more collaborative, inductive, field- and text-based research traditions that have been the most adversely affected.

We have entitled our report "Giving Voice to the Spectrum" to convey what we believe is the central requirement of any future evolution of the TCPS: that its next version acknowledge and respond to the diversity in research perspectives, reassert a commitment to principles of academic freedom, and ensure adequate protection for human participants. Doing so will require bold initiatives on the part of PRE to create an effective counterbalance to the biomedical/experimental hegemony that currently dominates the TCPS and that, according to the submissions we received, threatens the diversity of the

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[7] See also our discussion of this topic in Section 8(c) of this report—"Missing Fields of Study."

social sciences and humanities and their ability to carry out their traditional social and cultural mandate.

Deleterious Effects of the TCPS

We interpreted our mandate as one of identifying difficulties that researchers in the social sciences and humanities—and REBs reviewing proposals in the social sciences and humanities—had experienced in Canada's first five years with the TCPS. Researchers and REBs who are happy with the TCPS were thus unlikely to respond to our consultation, but we heard enough to know such parties exist, especially among those in the social sciences and humanities whose research subscribes to the epistemological perspectives that pervade the TCPS. For example, psychologists, many of whom engage in laboratory-based experimental research that conforms to the model of "human subject" research in finite and well-defined projects using standardized procedures, expressed few complaints with the TCPS. We also heard occasional stories of REBs who were appreciated for the thoughtful advice they gave and the insightful manner in which they ensured human subject protection while maintaining academic freedom, and who stayed within their mandate of *ethics* review.

More field- and text-based disciplines, and those engaged in more critical research, in contrast—that is, those whose work departs most significantly from the experimental/ deductive model that dominates the TCPS—were much more likely to make submissions and participate in consultations. And their message came through loud and clear: the first five years of implementation of the TCPS have yielded negative consequences for them, in exchange for what they are convinced is no gain in the protection of research participants. Researchers told us of projects that they say failed because of REB insistence on requiring signed consent statements, for example, even in situations where the existence of this paper trail could imperil participants. Another REB reportedly limits confidentiality but then apparently does not prevent researchers from asking participants for sensitive information that could harm them if disclosed, saying that as long as participants are warned the researcher will disclose information if pressured, the researchers are covered ethically; that is, a *caveat emptor* approach to research ethics.

The submissions recount stories in which REBs with no familiarity with the proposed methods and no experience with the research, research site or population, impose requirements that leave researchers frustrated because of what they view as impediments to ethical practice. Some students reportedly have ended up paying extra tuition because of semesters added to their programs while they underwent unnecessarily protracted ethics review. Students and faculty researchers have been told by their supervisors and REBs, or concluded on their own, that they should avoid certain well-established approaches and methods that their REB saw as threatening, presumably because of REB members' unfamiliarity with and/or lack of respect for the epistemological traditions and relationships on which these approaches thrive. Other researchers reported they have changed research areas rather than engage in what they view as fruitless negotiations with REBs that impose solutions the researchers believe are unworkable and/or unethical.

The submissions suggest that the ability of social science and humanities researchers to engage in and fulfil their traditional mandate to gather information about and critically

analyze all aspects of society is being threatened by a narrowing of permissible topics and approaches that has nothing to do with "ethics" and everything to do with non-ethics criteria such as liability management and other forms of "ethics drift"." This has infringed on academic freedom. They ask that bold steps be taken to safeguard the social sciences and humanities from a system of ethics review that was written with biomedical/experimental research approaches in mind and includes the rest of the social sciences and humanities merely as "other."

How Extensive a Change is Necessary?

All members of SSHWC are convinced that change to the TCPS and its structures of ethics review are required to more effectively give voice to the full spectrum of research perspectives and approaches that characterize Canada's social science and humanities research communities. The challenge is to determine just how extensive a change is necessary to mitigate the more deleterious and unintended consequences brought to our attention by the submissions. To do this, SSHWC considered the following:

Option 1: More Discussion, More Examples

One way to look at the problems created by the TCPS is to see them solely as problems of information deficiency, that is, problems that have arisen because definitions in the TCPS do not yet reflect the diversity of research traditions and methods that exist in the social sciences and humanities. One way to deal with that difficulty would be to maintain the current structure of the TCPS but to go through and supplement specific sections with broader and more inclusive definitions and/or more examples of how ethics concepts come to life in different social sciences and humanities research contexts.

Although an analysis of the submissions suggests that more information to help guide REB decision-making would be beneficial, this option is deficient to the extent it does not address some of the more fundamental structural issues that also undermine the TCPS. Indeed, when we made a preliminary attempt to work through exactly this option, we very quickly found it unworkable. The exercise reaffirmed that the TCPS must be seen as more than a list of topics; it also exemplifies and is organized by a certain logic about what research is and how it is done, and that part of the current difficulty arose because whole swaths of research "don't fit." If the next version of the TCPS is to be more inclusive, this alternative will not work. Any changes must go beyond the constraints of the current document and embrace other logics.

Option 2: Creating New Chapters on Issues in SS and H Research

One way to avoid the limitations inherent in Option 1 would be to create one or more separate chapters regarding research in the social sciences and humanities (SS and H). These would discuss the diverse array of methods and methodologies they practise beyond the more experimental/positivistic/deductive model that characterizes the current version of the TCPS (which, of course, also characterizes some SS and H research).

There is much to recommend that approach. Certainly, different default assumptions can be made about research in the social sciences and humanities than can be made about the prototypical clinical trial, for example. While basic concepts of research ethics are common

across disciplines—respect for human dignity, consent, confidentiality, conflict of interest and so on are equally central and important—the way they come to life in social science and humanities research contexts, and within the more qualitative/inductive/field-based research traditions, is sufficiently different to warrant separate treatment, and sufficiently important to warrant inclusion in the TCPS in a distinct chapter or chapters devoted to the range of social sciences and humanities research.

The creation of a separate chapter also would be symbolically important to social science and humanities researchers who engage in more collaborative and emergent approaches as acknowledgement that they are valued and their uniqueness is recognized. As there are already separate chapters in the TCPS that deal with other "specialty" areas such as Aboriginal peoples, clinical trials and human genetics research, the precedent is already there for including separate chapters dealing with non-experimental research and/or qualitative approaches. Such chapters would also provide a reference for both REBs and researchers to consult regarding epistemological and ethical principles and their application in different social science and humanities contexts.

However, there are limitations to this option. While it may go further than Option 1 in addressing informational needs by allowing additional material about social science and humanities research to be written on its own terms and according to its own logic, it suffers the same limitation as Option 1 by assuming that the problems with the TCPS are *only* informational. The submissions the Secretariat on Research Ethics received suggest that the problem is deeper than that, extending into processes of ethics review. The challenge for REBs to engage in sensitive ethics review that appropriately balances the need for human subjects' protection with the academic freedom that fuels a thriving research enterprise requires we also reconsider the ground rules that trigger and govern that review. In addition, a separate section may heighten the marginalization of social sciences and humanities research as "other" within a broader document that has, at its heart, the biomedical/experimental model of "research."

In SSHWC 's view, adding information without dealing with those structural issues surrounding review would be insufficient to ameliorate the difficulties the submissions drew to our attention. Indeed, any failure to follow through from those characteristics and assumptions that make much of the social sciences and humanities unique to the implications of those differences for the review process would only compound the problem. Accordingly, while the Committeebelieves this option is an improvement over Option 1, Option 2's lack of attention to the implications for review leaves it equally wanting in that respect.

Option 3: More Information *and* Context-Appropriate Processes of Review

A third alternative involves providing more information, as described in Option 2—a separate chapter or chapters dealing with social sciences perspectives and illustrations of how the TCPS's core ethics principles play out in a range of social sciences and humanities research contexts—but accompanying that information with an array of procedural and definitional changes based on recognition that the qualities that distinguish much social

science and humanities research call for fundamentally different treatment by REBs in the way that ethics review is handled.

There is much in favour of this approach. It seems an effective compromise to the TCPS's aspiration to provide a single system of ethics review while recognizing there are unique and characteristic elements of much SS and H research that warrant a different approach to review and regulation than is required for the stereotypical clinical trial, for example. Whether this is sufficient to deal with the problems identified in the submissions we received is another matter, which depends in part on what one perceives "the problem" to be, and how far that definition of the problem extends beyond informational considerations and into other procedural and structural elements. These can include the default assumptions that apply to any given piece of social science research, and the composition of committees.

Option 4: Creating a Separate SS and H Policy on Ethics

A fourth option involves all that is described in Option 3, but goes on to assert that the issues, approaches, relationships and expertise that distinguish biomedical and experimental research from qualitative/inductive/collaborative models of research are so significant and pervasive in their implications that nothing short of the complete separation of ethics regulation of these two different fields will do. This option rests on the belief that both sets of practitioners and the research subjects/participants with whom they interact would be better served and protected with two different policies implemented by at least two different sets of committees operating on the basis of two different ethics review frameworks.

At one extreme, one can identify the biomedical clinical trial, whose regulation occupies much of the TCPS's focus. There is much at stake in this sort of research, which involves a human being (often an individual who is vulnerable because of a condition that some new drug offers the hope of alleviating) who is volunteering to be the guinea pig—very much the "human subject"—for a new drug or other therapeutic regimen. The research itself is highly legally regulated and follows a paradigmatically predetermined path—with a clear beginning and end—from phase to phase and trial to trial. The subject's role is very clear and exactly the same for every subject except for the presence or absence of the therapeutic intervention being assessed. There are always risks to such research—sometimes up to and including death, which has happened more than once in the recent past.— The "minimal risk" project is the exception rather than the rule.

At the other extreme of the research continuum is qualitative/inductive research that can proceed down any of a number of different paths, depending on where the cross-collaboration of researcher and research participant leads them. Depending on the type of research being conducted, their relationship may last anywhere from weeks to decades. It is likely that over that period, they will interact in a number of "research" and "non-research" roles that will blend in various ways, depending on the circumstances and occasion. Either individual is likely to be the initiator of any given interaction, whose flow can range from highly predictable to unanticipated. In most cases, it is unlikely that any significant harm could befall the participant, and any threats that do exist are likely to come from *outside* the relationship rather than from procedures or stimuli to which the researcher is exposing the participant. Any REB effort to overlay a legal framework on their relationship—through

the requirement of signed informed consent statements, for example—would be resented by both sides for ethical reasons as much as anything else. They would see it as a sign of hierarchy, with the researcher lording his or her credentials and institutional authority over the participant. Each is there because they want to be. Either can leave if there is no longer any basis for interaction, or the trust and rapport they share are broken.

Both these scenarios are to some extent caricatures of their respective traditions, but they highlight some of the elements that distinguish the two traditions: different prospective harms, different relationships, different conceptions of what "research" is —and when and if it makes any sense to call it that. The degree of intervention that would be considered "normal" or "essential" in the biomedical scenario would be perceived as "alarmist" and "excessively bureaucratic" in the other. Risks are expected in one; they are exceptions in the other. The relationship in one is professional and caring, but as aloof as the relation between an accountant and his or her client, reflecting the methodological dictum that valid data arise from an impersonal objectivity that is best accomplished when roles and purpose are clear and limited to the purpose of the research. An epistemological imperative for the field researcher, in contrast, is that valid data emerge from mutual trust and rapport that arise from extended intimate contact with persons in their natural context. The first seeks generalizable knowledge; the latter understands facts as contextually contingent constructions that may or may not have a reality beyond that milieu.

The argument for separate codes of ethics, differently constituted REBs and completely separate processes of ethics review rests upon an understanding that entirely different sets of expertise are required in order to achieve sensitive and thoughtful ethics review within each tradition. Research participants and the integrity of the research enterprise and of ethics review processes are best protected when the persons undertaking review have expertise in the methods under study, and the contexts in which the research occurs. Although anthropologists, sociologists, political scientists and criminologists may have insights to offer if they are to participate in the ethics review of a Phase II clinical trial, the protection of research participants and the integrity of the clinical trial will be maintained best if the persons undertaking review are experts in human physiology, understand pharmacology and the legal and clinical requirements of such a trial, and can anticipate the scenarios that might arise and how they should be dealt with. Similarly, although a neurosurgeon, kinesiologist, engineer, and cancer specialist who undertakes clinical trials reviewing field research may have insights to offer on a proposal for an ethnography of intravenous drug users in the downtown core of a large city, the protection of participants and integrity of the research would seem better accomplished when the persons undertaking review are individuals who have experience with the study's methods, milieu, and the kinds of problems that arise in such settings.

A fundamental premise of social science research ethics, particularly among disciplines and approaches that emphasize collaborative, inductive and field-based research strategies, is that sensitive ethics decision-making requires close familiarity with the research site and research population involved. If the TCPS means to pay more than lip service to the need for epistemological respect, and if practitioners of the more qualitative/inductive/collaborative field traditions are to be accorded respect for their traditions, then ethics review must happen on terms that are epistemologically meaningful to them, and not on the basis of any other tradition's criteria.

An implication is that it is only by creating separate ethics codes for the social and biological sciences that appropriate expertise can be brought to the task in both domains and thereby maximize benefits for research participants/subjects and the research enterprise itself. Any cross interest—for example, where health researchers undertake more qualitatively driven social science research, or where social science researchers look at physiological processes and interventions and follow more experimentalist models with a clear researcher-"human subject" relationship (see also discussion of these concepts below)—would require researchers to seek approval from the appropriate committee based on the research area and its methodologies, rather than their own disciplinary base. This would ensure that projects are reviewed by committees with the expertise and experience required for sensitive ethics review.

Implications for Change

▪ Deciding among the four alternatives described in section II is as much a policy question as a pragmatic one. The SSHWC recommends that Option 1 (minor revisions to the existing TCPS, leaving its current structure intact) and Option 2 (a new chapter on ethics in the non-experimental social sciences and humanities) be rejected as insufficient. PRE should seriously consider Option 3 (a separate chapter and adapted processes of ethics review) and Option 4 (two completely separate ethics policies: one for the social sciences and humanities, and one for the biomedical/experimental sciences).

III. Priority Areas for Reconsideration

Regardless which alternative PRE chooses, consideration must be given to the problems drawn to our attention by members of Canada's social science and humanities research communities. Based on our review and discussion of the several hundred pages of written submissions we received, plus the in-person sessions each committee member attended, 27 categories of issues were initially identified and brought forward (see Appendix D). Further discussion and a winnowing and re-organizing of these issues brought consensus that the eight issues described below are the ones that most urgently require attention in any subsequent evolution of the TCPS and/or Canada's ethics infrastructure. The order in which they appear below does *not* necessarily reflect their priority within the list; we chose the order simply because it flows chronologically from overarching ethics review concerns, to the decision of whether and when ethics review is triggered, to the principles applied to that review, followed by more specific considerations.[8]

1. Affirming Academic Freedom in Ethical Inquiry

After acknowledging in its preamble the general benefit to society of free inquiry and the independence of higher education in Canada, the TCPS shifts immediately to a discussion of responsibilities that modify academic freedom. These are asserted, in part, as the price

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[8] The order in which SSHWC would consider these issues in its workplan under a proposed new mandate is discussed in a separate briefing document to PRE.

for "the privilege of conducting research on human subjects with public monies, trust and support" (p. i.8). Submissions that comment on this aspect of the TCPS state that the responsibilities, which the researchers are quite prepared to embrace, have not been balanced with appropriate safeguards for academic freedom. For some researchers, this has made the TCPS's allusion to academic freedom an empty promise.

Academic freedom and its relationship to an ethical framework and to ethical standards deserve more consideration in the TCPS preamble. Structural changes may be necessary to ensure that REBs that might use the qualifications as a vocabulary of censure are held in check. Impediments to academic freedom within the current TCPS structure need to be counterbalanced by assertions and processes that make infringement of academic freedom difficult. Our analysis of the submissions revealed that if such problems arise, there are several key moments of the review process in which they are most likely to appear.

In many institutions, the REB chair or a Director of Research Ethics acts as the REB's gatekeeper. Such a role can be very useful in ensuring that proposals are ready for consideration and in identifying proposals that meet criteria for expedited review. However, some of the submissions indicated this was also where the worst infringements of academic freedom happened; that is, when the REB gatekeeper would refuse to consider or would attempt to "re-package" proposals in a language that spoke to the TCPS's default categories and catered to the preferences of that particular REB. This seemed particularly troublesome for researchers proposing more qualitative/inductive/ collaborative methods, where it would be contrary to the epistemology and ethics of that research to predetermine the focus of study without discussion with persons in the research setting and/or extensive exposure to the setting itself. This left researchers feeling that they were in a Catch-22 where they could not develop a focused research question without interaction with the setting and those in it, yet could not engage in such interactions until they identified a focused research question to the REB in order to receive its approval.

Once past the gatekeeper, proposals normally would go to the entire committee for full review or, at minimum, ratification of the gatekeeper's decision. For matters that go to full REB review, the TCPS's aspiration to create an ethics review process implemented by a broad-based committee that acts as a quasi-representative microcosm of society is laudable. But some submissions noted committees constituted in this way lack the specialized expertise for sensitive ethics decision-making in context. We suspect the problem is particularly acute at institutions that have only one REB to field all proposals—perhaps in keeping with the wording of TCPS article 1.4 (on p.1.4), which seems to favour fewer and bigger committees—making it extremely difficult to provide the full range of expertise required to adjudicate proposals. Although our evidence for this conclusion is limited (and might, in itself, warrant further investigation), our impression to date is that having more committees—where "more" means at least two, with one covering more biomedical/experimental/ physiological "human-subjects" research and the other dealing with non-experimental research in the social sciences and humanities—creates a better balance because of the higher likelihood that committee members will possess appropriate epistemological knowledge and experience.

A new set of problems arises when REBs intervene on issues that are irrelevant to ethics consideration, but are introduced in the TCPS. For example, the TCPS states that "duties of

honest and thoughtful inquiry, rigorous analysis, and accountability for the use of professional standards…peer review of research proposals, the findings and their interpretation contribute to accountability, both to colleagues and to society" (p. i.8). These unqualified comments appear to lead some REBs to believe they have an open mandate to adjudicate whether an inquiry is "thoughtful" (a highly subjective judgment that opens the door to epistemological bias), whether analysis is "rigorous" (something better left to peer review in the discipline), whether "professional standards"—beyond ethical standards—are being met. Some submissions ask why, except in cases of risk, would the TCPS concern itself (and REBs) with "peer review of research proposals"?

Even though the TCPS asserts that peer review should happen only in the case of proposals that expose participants to greater than minimal risk, the submissions we received claim that some REBs violate the policy by doing so routinely, justifying their actions as something that is "more ethical" than the "minimal standards" espoused by the TCPS. Problems would be compounded, and academic freedom could be inappropriately limited, if "peer reviews" were done by REBs who lack the range of expertise to adequately make such judgments.

Especially troublesome is the TCPS's comment about review of "the findings and their interpretation" (p. i.8). If this is an ethical matter, how is it? If it is not, what is it doing in a document on ethics? By making specific reference to research findings and their analysis, the TCPS may be seen as requiring that *conclusions* reached by researchers meet some ethical standard, such as not harming participants or the community of which they are a part. But a central mission of the university is to engage in informed and thoughtful criticism of all elements of society. At times this may involve showing how a particular group is corrupt, engages in self-aggrandizing practices to the detriment of its clientele, and/or is using its monopoly in a manner that is counter to the researcher's view of the public good. Expanding ethics review to a study's conclusions could stifle legitimate debate about controversial social issues. Academic freedom might be trumped by the "responsibility" that is claimed to modify it. Researchers cannot guarantee that their findings will not "harm" some social group, no matter how diplomatically those findings are put when published. This difficulty is not adequately discussed in the TCPS, leaving one with the possible conclusion that any study that could produce conclusions that violate an REB's view of "respect for human dignity" ought not to be approved in the first place.

As one submission noted, the TCPS seems to assume that Canada is a homogeneous society where consensus exists as to who the heroes and villains are, when that is clearly not the case. Academic freedom exists when researchers are encouraged—and their right defended— to study controversial topics and hold unpopular positions. The structure and powers of the REB outlined in the TCPS require a counterbalance to ensure that ethics review is not used as a conduit for non-ethics criteria such as ideological conservatism, or institutional/researcher concerns about liability. Will REBs protect the right of researchers to undertake critical research and investigate options that threaten opinions held by members of the REB? The TCPS says they should, and some do, but according to the submissions we received, the REB track record is far from perfect.

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Implications for Change

- The TCPS should more explicitly affirm the necessity of academic freedom for a healthy research enterprise; remove reference to "responsibilities" that do not bear directly on the task of ethics review; state that it is unethical for REB members to infringe academic freedom; and indicate that REB decisions can be grieved using whatever mechanisms exist at the researcher's institution, when and if an REB strays beyond its mandated domain.

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2. "Research," "Subjects" and "Harm"

When an ethics review structure that is designed to deal with cases that are common to biomedical research is the same one that deals with social science and humanities research—as has been the case for five years now in Canada—the submissions we received affirm that the result is often less than ideal. Part of the problem lies with the set of default assumptions the TCPS imposes upon REBs: that "research" is a discrete category of human activity that is easily demarcated, that every research project is risky unless shown otherwise, that every research proposal involving human participants requires intense scrutiny unless decided otherwise, that written consent is required unless demonstrated otherwise, and so on. These defaults assume a particular model of research that is anything but typical in the social sciences.

In considering what might be done to alleviate the problems that researchers and research administrators drew to our attention, we started by looking at the domain for which the TCPS claims jurisdiction and what the structures articulated in the TCPS seek to accomplish. Stated in its simplest terms, the TCPS deals with "research," and is concerned that "human subjects" should be protected from "harm." We then considered the meanings of those three concepts in relation to the social sciences and humanities, and asked whether the TCPS adequately reflects the diverse conceptions of "research" and "human subject" held throughout the full spectrum of research involving human participants. It does not.

2a. A Narrow Conception of Research

Article 1.1 of the TCPS defines research as "a systematic investigation to establish facts, principles, or generalizable knowledge" (p. 1.1). The submissions we received suggested that ambiguities in this definition, combined with TCPS "defaults" that every research project should be assumed to involve risk and require intense scrutiny until demonstrated otherwise, has led to what one submission referred to as "ethics drift," wherein REBs have gradually expanded their jurisdictions to the point where any interaction with persons who might end up being participants, or any interaction in which information is shared, is considered "research," and is thereby a prospective source of risk.

The vision of research that currently dominates the TCPS is one in which "research" is a unique category of easily identifiable activity that happens with predetermined persons in predetermined places according to predetermined procedures, the aim of which is to produce generalizable facts. This narrow conception of research dismisses whole research

traditions—particularly more inductive and collaborative field-based traditions—as something less than "research." Here are some examples:

- Many social scientists set out no intention whatsoever of establishing "generalizable" facts, because they see facts as social constructions that cannot be considered outside the context that makes them real. Accordingly, they eschew generalizability in favour of emphasizing the need for integrity of data collection and analysis with the case at hand.

- In many approaches, the boundaries of the research process are far from clear. This is particularly the case with field researchers, who may spend their whole careers dealing with one research venue—a community or particular subculture, for example—that involves sporadic crossing of paths and a constant flow of interaction, occasionally in interactions both researcher and community member might formally recognize as a "research" interaction, but just as frequently not.

Because the TCPS does not, in our opinion, adequately recognize these traditions, and some REBs may be constituted without members having appropriate expertise to adjudicate proposals, some REBs may have difficulty when the line demarcating "research" is so amorphous. They might end up choosing control and intervention consistent with the risk-avoidance model that permeates the TCPS, apparently feeling encouraged to follow, to the extreme, the dictum of "Better safe than sorry."

These different definitions of research also imply different assumptions about what entails research. Researchers told us that when their proposals are reviewed by REBs unfamiliar with their methods and approaches, the REBs start to drift beyond their mandates. In some cases, they are reported to have questioned the scholarly merit of work that does not conform to TCPS or REB definitions of research, even when that research has gone through peer review and been funded by the Social Sciences and Humanities Research Council of Canada (SSHRC), and has negligible potential to cause harm. These alleged infringements of academic freedom are beyond the mandate of REBs. Thus they offend researchers, who feel they are being forced to adopt foreign epistemological criteria that undermine their research and their positive relationships with research participants.

Implications for Change

- The TCPS definition of research must recognize the diversity of ways that "research" is constituted in SS and H research communities. It should include discussion of how the ethics review process can be adapted in a manner that shows respect for traditions such as inductive and collaborative field-based approaches, or textual research, that are most compromised when expectations based on the narrower definition are imposed.

2b. When is Someone a "Human Subject"?

The narrow conception of "research" in the TCPS is accompanied by an equally narrow conception of "the human subject." Early in the TCPS (footnote 2, p i.3), a defining statement is provided about human subjects:

During preparation of this *Policy Statement*, there was extensive discussion of the optimal term to describe those on, or about whom, the research is carried out. This discussion focused on the terms "participant" and "subject." Though research subjects may participate actively in research, so also do many others, including the researchers, their staff, administrators in the institutions, and funding sponsors and members of research ethics boards. Research subjects are unique amongst the many participants because it is they who bear the risks of the research. The Councils have therefore chosen to retain the word "subject" because of its relative unambiguity in this context, and because the prime focus of the *Policy Statement* is on those who bear the risks of research.

This statement may be unambiguous when there are clear distinctions between researchers and subjects, as occurs in biomedical and experimental research, but this is far more elusive and ephemeral in many SS and H projects. First, the statement that it is only participants who bear research risk is yet another laboratory/clinic truism that falls short in the field. Researchers observing gang behaviour, interviewing CEOs of wealthy companies with many lawyers and deep pockets, or doing ethnographies in remote locations are among many facing far greater risk than the participants in their research. The statement also does an injustice to researchers who were prepared to go to jail rather than betray the confidence of their research participants and expose them to harm, and who otherwise have intervened and put themselves at risk to protect the participants of their research.

Second, when the place one does one's research is not the laboratory but daily life, the multiple and divergent roles humans adopt intersect with the research relationship, problematizing any neat distinctions between the researcher and a "human subject." Collaborative and participatory research engages members of a community as co-researchers as well as research subjects. In self-reflexive, autobiographical and auto-ethnographic research, researchers become a focus for the research, such that the researchers are simultaneously researchers and subjects of the research.

Individuals also can be involved in information gathering activities without becoming either researcher or human subject. This is the case when those individuals are involved in basic consultation tasks with no conceivable potential for harm. Examples include the following situations:

- A librarian is asked to identify useful reference materials or resources.
- A linguist overhears an unusual phrase or pronunciation in a day-to-day encounter and asks where the speaker is from.
- A community professional with whom we share a common interest, and who has been a "research subject" on other occasions, runs into us at a conference where she is giving a paper about an ongoing research project on which we collaborated and for which she was interviewed.
- Audience members' reaction to a theatre performance is noted.
- A member of a First Nations community comes into a museum, sees an artifact and tells the curator about the significance of the piece in his family's history.

- E-mail forum participants are asked to identify what they believe are important sources for a planned literature review.
- Researchers at a university are asked to identify what they believe are problems with the administration of the TCPS.
- A teacher asks for feedback from colleagues and community members about a proposed lesson plan or handbook.

These examples—which involve activities some REBs have considered "research" involving "human subjects" and thereby asserted are subject to ethics review—raise the question of what it means to be a "human subject" and thereby to involve an interaction that triggers ethics review. Obversely, researchers ask why, in a free and democratic society, interactions between a researcher and anyone who is not acting as a "human subject" should come under ethics review in the first place.

Certainly, if the purpose of ethics review is to protect research subjects from harm, then it follows that ethics review is unnecessary when no likelihood of harm exists. Just because someone has provided some information that can be construed as or might someday become "data" does not make that individual a "human subject." In the examples above, the consultations occurring provide no conceivable potential for harm to the participant— they involve free interactions between consenting persons. Any subsequent use of the information will be anonymous or fully attributed (for example, in the case of another conference participant with whom we chat over lunch). Therefore, the consultants do not, in our view, constitute "human subjects." Consultants need to be treated with respect, and interactions need to follow professional standards, but no ethics review is required for such work.

Following from this consideration is the issue of who determines that there is no prospective harm. The researcher, who thereby does not even need to apply for ethics review? Or the REB, who determines whether the research meets the criterion and, if so, proffers the exemption? Each approach has advantages and disadvantages. SSHWC is less concerned at this time with who invokes the exemption than with the provision that such an exemption be provided for in research that involves no prospective harm.

Implications for Change

- Further discussion is warranted in the TCPS regarding what being a "human subject" entails. We suggest that being a "human subject" implies a power differential between researcher and participant that arises from the nature of the relationship, conflict of interest, clear subject incapacity and/or opportunity for coercion. In the absence of such indicators, we suggest that PRE exempt such research from REB review, and consider social science- and humanities-appropriate mechanisms through which that exemption might occur.

2c. Reconsidering "Minimal Risk"

Researchers are concerned that the guiding logic of "minimizing risk" is often misunderstood or misused by REBs. Many of the submissions we received expressed concern that REBs regularly overestimate both the magnitude of risk that is involved in their research and the probability of those risks being realized—leading to the accusation that REBs are intervening in research and trying to create zero risk. Considerations of risk need to be balanced with the prospective benefits that may accrue for the project. An overemphasis on risks can create barriers to participation for groups who see researchers as their allies (for example, marginalized groups who recognize researchers as persons who will treat them with dignity and respect and will give them voice) and not their enemies.

Confusion of this sort on the part of REBs emerges, in part, from the TCPS's operating assumption that those who participate in research are "human subjects" who must be protected from a powerful researcher. However, the assumption that "research involves risk" is questionable in social science and humanities research traditions that emphasize collaborative approaches that seek to maximize the joint benefits of research and establish long-term collaborative relations built on ongoing mutual trust and respect. To the extent that harms exist in this type of SS and H research, they rarely exceed the sorts of harm we are exposed to and experience in everyday life, and are more likely to arise outside the research context.

Instead of being thanked for their intervention, REBs are resented by researchers and prospective participants for denying persons the opportunity to participate in research. We suggest that social science and humanities ethics review should begin with the default assumption that risks are minimal. REBs should refrain from requiring changes in the design of the research unless there is a clearly identifiable and significant prospective harm that researchers have not considered and that thus requires their attention.

Implications for Change

- Designating a subset of studies "minimal risk" may make sense in areas such as biomedical research, where risk is always present and "minimal risk" studies are the exception. The concept is less useful when virtually all research is "minimal risk," as is more commonly the case in the social sciences and humanities. For social science and humanities ethics review, we suggest the TCPS instead focus on the notion of "identifiable harm." Only in instances where some clearly identifiable and significant harm is likely and requires mitigation should REBs be empowered to require alterations in research design. Development of an inventory of significant harms that warrant REB review, and minimal harms that do not warrant review, should also be considered.

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3. Scope and Level of REB Review

As the preceding section outlines, the default assumptions that apply in the social sciences and humanities are different from those that apply in the biomedical realm. If the TCPS is to "give voice to the full spectrum of research" that occurs within the social sciences and humanities, the challenge is to determine ways that might be accomplished. As advisors to PRE who have felt the pulse of Canada's social science and humanities research communities, it behooves us to consider those issues.

3a. Assumptions/Observations About SS and H Research

We begin with some default assumptions and observations about social science and humanities research, particularly with respect to more field-based traditions:

- Research sometimes is easily recognizable as a discrete activity in the social sciences and humanities, but it is also the case that, at the opposite extreme, some "research" engagements can almost be considered a "lifestyle" insofar as they involve ongoing interactions—both scheduled and serendipitous, both structured and informal, in the context of formal "research" interactions and other—that may occur over years or even decades.
- While some research involving human participants engages those persons in more legalistic relations as "subjects" of the research, much SS and H research does not. Instead, it aspires to more collaborative and egalitarian relations built on mutual trust and respect. These are undermined when a legal framework is imposed.
- Harm greater than that we deal with in everyday life is the exception rather than the rule in SS and H research.
- A central tenet of most SS and H perspectives is that responsible and caring ethical decision-making in the social sciences requires familiarity with the people and the site in order to best understand the complexities and trade-offs involved when ethics issues come to life in that context.
- SS and H researchers collectively encompass diverse research perspectives involving a similarly wide array of methods and research sites. Thus, it is highly unlikely that any finite/manageable number of persons on an REB will have an adequate range of expertise and experience to make reasonable ethical decisions about the specifics of that research site and population.
- Research practices in the social sciences and humanities are taught on a mentoring or apprenticeship basis, where faculty supervisors with experience in a particular area, population or site introduce a supervisee to the site. This includes a tour of ethical issues that must be considered in that domain, and disciplinary-based desiderata for resolving them.
- The "education and responsibility" model of ethics review has been a very successful strategy within the social sciences insofar as the social science track record contains very few "ethics horror stories," and none that parallel those that have proliferated in the biomedical domain (which are the ones cited whenever the need for ethics review and oversight is affirmed).

These default assumptions that are appropriate to social science and humanities research are very different from the default assumptions that characterize, for example, the biomedical domain. Recognizing the divergent methodological models that characterize the

social sciences and humanities requires commensurate shifts in approaches to ethics review that reflect those differences. In our own discussions on this matter to date, we have come up with several possibilities that operate at the nexus of three concepts discussed above: "research," "human subject" and "harm."

3b. Establishing "Research Program" Review

We have already urged PRE to consider promoting a definition of "research" that more accurately reflects the diversity of approaches that researchers following different traditions bring to their work. In order to deal with the situation of field researchers practicing emergent (inductive) methodologies, we suggest PRE consider implementing an approach to review based on *programs* of research rather than one based on review of discrete projects.

Implications for Change

▪ PRE should consider establishing a "program review" model of research ethics approval in cases where research involves extensive, emergent and collaborative activities in the field. This could be done by allowing researchers to apply for a "research program" that would stay in effect for years at a time, and would specify a general set of parameters in which the research would operate. This program would have de facto REB approval until such time as the parameters changed. At that point, the researcher would prepare a new proposal or simply file an addendum.

3c. Exemptions from Ethics Review for "Standard Professional Practice"

Every discipline has standard scenarios that are routine. As it now stands under the TCPS, every research project, no matter how routine, is subject to ethics review. The load facing REBs could be reduced considerably, with no loss to the rights and interests of research participants, and safeguards for academic freedom enhanced, by exempting research that involves "standard professional practice." For example, the TCPS might recognize that a given set of social conditions—where a researcher gathers data from other citizens in social exchanges that everyone in that society has a right to engage in, and where strict confidentiality governs any reporting of individuals' observations—constitutes a routine activity and should not require ethics review. This approach has the added benefit that REBs would gain more time to deal with unusual, potentially problematic research that warrants their attention.

Such an approach might assert that research ethics review or possible intervention is triggered only when the research involves a "human subject" as discussed above (see section 2b), and/or when a clearly identified "harm" is involved (see section 2c). REB involvement would be triggered only when the participants in the research are indeed in the relationship of researcher and "human subject"; that is, where the latter is in some way captive, vulnerable, identifiable, and/or of limited capacity, and/or when there is a concrete and reasonable expectation that harm is likely, and then only to the extent required to

demonstrably ameliorate that harm. If none of these red flags were present, no review would be required. As discussed previously (in sections 2b and 2c), a matter to be considered is whether the researcher makes these judgments, or submits a proposal to the REB, which would ensure that articulated criteria are met.

Implications for Change

- PRE should consider investigating "standard professional practice" across a range of social science and humanities disciplines with an eye toward developing a workable scheme of ethics review that operates within the broader TCPS framework, while more effectively balancing legitimate concerns regarding human subject protection with the right of researchers and citizens to interact free of regulation in a democratic society.

3d. Shifting the Onus

The alternative above is agnostic with respect to whether researchers would seek ethics review only when specified criteria were met, or be required to submit a proposal that the REB would review to determine whether the criteria for exemption had been met. In the event PRE decides on the latter strategy, some significant counterbalance is required to ensure that REB intervention is selective and limited to *ethics* review. An effective mechanism toward that end would involve shifting the onus with respect to considerations of harm and the ability of an REB to intervene in the research design.

Implications for Change

- Before requiring changes to a research plan, an REB should identify a concrete harm that has some likelihood of occurring, and has the onus of demonstrating that the ameliorative action it proposes has a better likelihood of alleviating that harm than the resolution offered by the researcher.

3e. Standardizing the Delegation of Authority for Course-Based Research

Research in the social sciences and humanities works on an apprenticeship model, in which course and thesis supervisors gradually introduce students to the rigours and ethics of research, with progressively greater seriousness of topic and autonomy of action being gained over time. REBs lack the disciplinary and site-specific knowledge to effectively mentor student researchers, thereby undermining ethics training that is properly taught via disciplinary-based instruction that introduces students to the unique ethics issues that arise when addressing the research questions and dealing with the research sites and populations that characterize that discipline.

4. Consent

Perhaps no single statement in the TCPS is more in need of re-thinking than Article 2.1(a), which states that research "may begin only if (1) prospective subjects, or authorized third parties, have been given the opportunity to give free and informed consent about participation, and (2) their free and informed consent has been given and is maintained throughout their participation in the research" (p. 2.1). This relegates well-established and recognized methods of whole scholarly domains into ethical purgatory—virtually all inductive, collaborative and emergent field research, for example—and is yet another example of how standards that make sense in one field can create problems in other fields where those "standard" assumptions are anything but standard. It is believed that the imposition of research-design standards from one field onto other fields undermines the accepted traditions in those other fields. Hence, it undermines academic freedom.

4a. Consent is a Relationship, Not an Event

In the social sciences and humanities, consent is viewed as a complex process that differs from one type of research to another. In some cases it is impossible to gain consent in advance because one cannot anticipate the event (for example, social responses to the ice storms in Quebec), or it is the participant who seeks out the researcher (as in these examples: a member of a First Nation sees a family artifact on display and wants to tell the anthropologist curating the exhibit its history; the owner of a brothel calls a trusted prostitution researcher offering to tell him all about the business). In other instances, it may be undesirable to "seek consent" in advance because participants are also collaborators who jointly determine project directions and protocols, and "initiating a consent agreement" imposes a hierarchical relationship that undermines the collaboration.

In other traditions (such as participant observation), the investigator does not know who might be a potential subject until he or she has spent some time in the milieu and has refined the research question. For the same reason, it is often difficult to determine just where a project "starts." In many field traditions, it is also the case that consent is not a "one-time" event, but rather something that is re-affirmed simply by maintaining contact,

or agreeing to enter the next stage of a process, and/or is placed in abeyance while some new set of understandings is being developed.

4b. A Preference for Oral Consent

In some research traditions, a signed consent form is viewed as a neutral document that merely demonstrates to the REB that proper information has been conveyed to the participant. In contrast, the signed consent form in most cases does virtually nothing for the subject in social science and humanities research. Quite the opposite: it is more likely to undermine participants' interests than to affirm or enhance them. Although the TCPS gives some examples in which a consent form may not be necessary, researchers whose work is more collaborative than the TCPS contemplates tell us their work is thwarted by REBs, which treat the signed consent form as the default expectation—which it clearly is not in the social sciences and humanities—unless the researcher is willing to spend the time making a persuasive argument to the contrary. These defaults should be changed in the new version of the TCPS for social science and humanities research, where, in most cases, the signed consent form is redundant and creates unnecessary formality and impedes research. Researchers expressed resentment over the imposition of a legalistic framework on a relationship that is maintained by mutual trust.

Consent is also typically more an oral than written process in the social sciences and humanities. This is due to respect for the meaning and purpose of consent, which is not to put everything on paper (a means rather than an end), but to engage in a dialogue that makes it easier to ensure that the research participant understands what his or her participation will involve. As one submission stated, "The TCPS should be concerned with the principle of establishing trust relationships rather than with the process of documenting them." Subjects may not understand forms; many studies show that words and phrases in consent forms are not understood by the populations from which subjects are drawn— including words such as "withdraw consent," "compensation" and "waive your rights." These studies typically use forms that have been approved by ethics committees. As one code of ethics puts it, "it is the quality of the consent, not the format, which is important." Too much detail about a project in the consent process, including on the consent form, may confuse the subject and have the paradoxical effect of making a subject who is given too much technical detail as ill-informed as one given too little.

4c. Deception, Debriefing and Data

Some disciplines, such as social psychology, make extensive use of deception (euphemistically called "partial disclosure" in the TCPS). The TCPS rightly suggests that some research cannot be conducted if the subjects are fully informed in advance. In most cases the subject is given the information after the fact. But the TCPS also permits the researcher to tailor the debriefing to the subject's sensitivities. It encourages use of a procedure whereby subjects can remove their data at the time of debriefing, but this option should be exercised *only* if "the elimination of the subject's data will not compromise the validity of the research design, and hence diminish the ethical value of participation by other subjects." Thus, present wording permits the researcher to gain an informed-consent exemption if the research cannot be done any other way, then permits the giving of a modified debriefing to be sensitive to the subject's needs and feelings, then legitimizes denial of retrospective opting out if such opting out would threaten research validity.

It is unclear how such a series of procedures is consistent with a subject-centred approach to research. The section appears to be a jumble of desiderata originating in experimental psychology (the justification of deception), generally accepted ethical criteria (ability to withdraw; heeding participant's feelings), and clinical trials (no withdrawal of data if validity threatened). It would seem another example where separate discussions of clinical trial and social science principles would result in a less confusing message to researchers and REBs, and enhance the ethical treatment of both sets of research subjects.

4d. Coercion

The TCPS applies the notion of voluntariness very broadly. It says that consent must be voluntarily given, "without manipulation, undue influence or coercion." The examples provided are not sufficiently helpful in specifying "manipulation" or "undue influence," or in reflecting the diversity of perspectives that exist with respect to this term. For example, many research communities view *REBs* as coercive! Although no doubt intended as caring by REBs, from participants' perspective the REB can be seen as coercive when it imposes perspectives and requirements on situations; sends memoranda or policy "pronouncements" on university letterhead; and invokes its authority and power to define the terms of relationships between researcher and participant without their consent, in a manner that neither may want.

4e. When Confidentiality Mitigates Lack of Consent

Researchers, like all other members of society, should have the right to talk with each other, ask questions, make note of answers, and write about them (in notes, stories, articles) anonymously without a requirement for formal ethics review (as is common practice, for example, in journalism). When harm is unlikely, ethics review is redundant.

On a related point, submissions indicated some REBs balking at the prospect of researchers accumulating photographic records or other observations of persons where the nature of the event and the number of persons present make the acquisition of explicit consent from all present impossible. We see no reason to obstruct the research when researchers have taken appropriate precautions to ensure confidentiality of information so that there is no possibility of harm to the participant.

Implications for Change

- Default expectations for how and when consent will be negotiated, what information will be provided, and the need for signed consent forms should all be changed to recognize the impact that differences in relationships, research contexts, methods, and methodologies used by a broader variety of disciplines have on the desirability of particular approaches to ensuring consent. Researchers and REBs should attend to general principles concerning consent in the context of possible harm.

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5. Privacy and Confidentiality

Comments and suggestions made in consultation sessions and written submissions led SSHWC to conclude that the TCPS discussion of privacy and confidentiality requires a

major overhaul to reflect ethical norms and standards across the diverse array of contexts in which Canadian researchers do their work, and the varying epistemological approaches they bring to that task.

The general directive now contained in Section 3 of the TCPS, which makes the strong assertion that "information that is disclosed in the context of a professional or research relationship must be held confidential" is both appropriate and important. However, four sets of issues arose in the submissions that require attention in order to better clarify how that overall objective is to be achieved.

5a. Anonymity/Confidentiality is the Participant's Prerogative

In keeping with the general TCPS principle that REBs must adopt a participant-centred perspective, the TCPS does not follow through with this idea in its prescriptions for confidentiality. Considerations of "voice" are crucial within several methodological traditions, and many researchers noted that attention to "respect for the dignity of persons" should normally recognize participants' right to ask to be identified and to have their views correctly attributed to them. In some research traditions and research sites, imposition of a rigid requirement that participants not be identified can reflect *dis*respect for the participant because of the manner in which it features the researcher's voice instead of the participant's.

Implications for Change

- The next version of the TCPS should give clearer direction to REBs and researchers engaged in field research regarding the variety of ways confidentiality issues can play out in various areas of research.

5b. The Divergence of Ethics and Law

Although researchers should make every effort to be both "ethical" and "legal," the confidentiality area is one where situations may arise where, as the TCPS states it, "legal and ethical approaches to issues may lead to different conclusions" (p.i.8). For example, in the United States, courts have on occasion ordered disclosures that the researchers involved believed were unethical, and where researchers were willing to go to jail to protect participants because of their view that ethics are paramount.

We are fortunate that no comparable situation has arisen in Canada, although there are two instances we know of where a researcher was subpoenaed - once by a Coroner and once by a Crown prosecutor - with the expectation the researcher would divulge confidential research information to a court. Although these were resolved successfully (with confidentiality intact and no participant harmed), the theoretical prospect of a divergence between ethics and law has generated among some researchers and REBs a certain apprehension to pursue, or allow the pursuit of, certain research projects thereby adversely affecting research participants. For example, prior to the existence of the TCPS, a Canadian university administration declined a researcher's request for legal representation, when he was subpoenaed and asked to divulge confidential research data to a Coroner's Court. The

university response left some researchers and some participants wondering whether universities will indeed be there to support them when and if it happens again. Years later, the university indemnified the researcher, and adopted policies for constructively addressing such matters in the future. If policies or universities do not do so, society's most marginalized and vulnerable research participants may be among the worst affected. (The TCPS has also since provided some guidance in this regard.)

Undue divergence between ethics and law may negatively impact research into, and the understanding of, social conduct. For instance, our Committee heard how concerns about possible orders by a court to disclose research data gathered in confidence initially prompted an REB to require the inclusion of a statement about "limited" (as opposed to "strict" or "absolute") confidentiality in their informed consent form. Beyond concerns about academic freedom, researchers argued that the statement risked negatively impacting socially important research into sensitive areas like illegal, sexual or criminal behaviour. Our committee also heard how confidentiality may impact the methods and focus of some social science research. One situation involved a researcher who an REB obliged not to ask questions on illegal behaviour in a study where criminal behaviour was the focus of the research.

The examples suggest that undue divergence between law and ethics may lead to high ethical and legal uncertainty that disables researchers, REBs and socially important research. If not resolved, it may ultimately create a situation where many of society's most vulnerable persons are unable to have their perspective heard, and many of society's most pressing social issues—for which empirically-generated understanding is most crucial—cannot be addressed.

Implications for Change

- Because of the crucial importance of confidentiality for certain kinds of research, we recommend that PRE investigate legal mechanisms used in other jurisdictions (such as confidentiality certificates and privacy certificates) for resolving the theoretical disjunction between statutory legal protections and researchers' ethical obligation to protect participants by keeping identifiable research information confidential.

- In the interim, we recommend that the TCPS provide information on how researchers who gather sensitive information that would harm participants if disclosed can maximize legal protections for participants through common law legal mechanisms such as the Wigmore criteria.

5c. The Problem of "Heinous Discovery"

Although the current TCPS recognizes in section 3 that "The values underlying the respect and protection of privacy and confidentiality are not absolute," the discussion of when and under what circumstances this might arise, and the researcher's obligations when such circumstances do arise, is insufficient. The literature on this topic refers to it as the problem of "heinous discovery";—that is, the discovery by the researcher of something so heinous

that a higher ethic calls for some action on the part of the researcher that would violate his or her commitment to confidentiality (for example, the discovery by a social researcher that the research participant intends to commit a grievous harm to a third party).

Implications for Change

- The TCPS should incorporate a discussion of the problem of "heinous discovery" and of researchers' and REBs' responsibilities should such a situation arise.

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6. Data Retention and Secondary Data Analysis

The TCPS is vague about retention of research data, leaving REBs to make their own judgments—potentially arbitrary ones, or ones that are easy to manage administratively— about whether researchers should retain their data, and if so, where, how and for how long. Data analysis in much SS and H research—particular qualitative studies—extends over many years, and in some cases, the entirety of the researcher's career. The concept of a closed and final "end date" for the research is in opposition to the nature of SS and H inquiry. New projects regularly prompt further investigation of previously collected data, as SS and H researchers strive to develop their research program—a "life's work," in many cases.

These analyses must not be confused with "secondary use" (that is, the analysis of data originally collected for non-research purposes, such as school or medical records). Nor should there be an expectation that research data will be destroyed after the completion of the research project (for example, at the close of a three-year grant cycle). Appropriate anonymizing and/or archiving (to ensure security of the data and confidentiality of the research participants) is an important element of this research. In some cases (such as oral history, and some research in Aboriginal communities), it is also important that data be archived for future research use and/or public access. In all cases, it is important that research participants be informed about researchers' plans to archive and/or destroy data, and for the wishes of participants to be considered in any decision about retention, destruction, or transfer of ownership of the data.

Implications for Change

- The TCPS should acknowledge that issues of data retention are not as straightforward a matter as simply demarcating some Procrustean exposure date that is routinely applied. In the social sciences and humanities, many research programs do not have easily defined "start" and "end" dates, and researchers may have obligations to community collaborators and/or there may be other historical or research purposes served by data retention. Such matters should be negotiated among researchers, participants and, in some instances, the community.

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7. International Research

The provisions of Article 1.14 seem to confuse REBs. Local REBs have difficulty discovering whether a review mechanism exists in a foreign jurisdiction. Even more challenging is the assessment of whether the ethical and procedural safeguards in place are equivalent to those in Canada. REBs are left wondering about the extent of their obligation to assess the review mechanisms in the host country. The TCPS is unclear as to how inconsistencies between local and international requirements should be resolved.[9]

The TCPS section on "Research in Other Jurisdictions or Countries" is yet another example of a section that was written on the understanding that the research being referred to is something along the lines of a clinical trial, and another illustration of where unthinking imposition of Canadian standards can have deleterious effects on both the research and research participants. For example, we were told of an REB that tried to require a researcher to get signed consent statements from persons who would be killed if their governments knew of their participation. Some political scientists reported similar examples of endangerment caused by REBs unwilling to listen to researchers' understanding of the dynamics that exist in many Third World countries and/or those with repressive regimes.

More recently, we are aware of discussions in the biomedical realm in which protracted discussion of placebo-controlled clinical trials in developing countries has led to a strengthening of the requirement for consultation with investigators in host countries in order to ensure the research meets the needs of the host country. This is yet another example of a criterion that would be problematic if imposed on researchers in the social sciences and humanities. Many social scientists definitely do *not* want to go through official channels because doing so might endanger their informants. The danger—the same danger that exists in Canada when every interaction must be "official," "formal" and "authorized" by someone in power—is the creation of a social science built on the formal party line. The people who lose are the marginalized who would be too fearful of scrutiny, surveillance, arrest (and even worse in countries with repressive regimes), and so on if those in power suddenly became all knowing about who in their realms were talking.

Implications for Change

- The TCPS's new coverage regarding international issues should indicate that international involvements are more complex in the social sciences than the current wording in Article 1.14 indicates. Discussion is warranted of what some of these complexities might involve, and how they have been resolved in various research traditions.

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[9] Similar issues arise across jurisdictions in Canada.

8. Gaps in Coverage

8a. A More Inclusive Inventory of Methods

The TCPS does not adequately represent the variety of methods used by the broad spectrum of social science and humanities researchers. We heard from many who are frustrated by the narrow focus of the present document, which guides REBs to a traditional experimental or otherwise structured model of research in which such matters as the procedures to be followed and persons to be sampled can be fully known in advance.

REBS that lack the appropriate expertise and experience feel threatened by some methods and approaches with long credentials in the social sciences and humanities—such as participatory action research, ethnography, linguistic field work, and some textual analytic techniques—but that defy easy categorization in the TCPS. Unfortunately, the submissions we received indicated that some REBs have responded to this ambiguity with what appear to be infringements of academic freedom—attempting to re-cast research so that it fits the REB's or TCPS's categories of what research should look like—and an increase in surveillance and control.

During the public consultation process, researchers reported being told by REBs that they could not use particular methods (such as covert observation) or tools (such as recording devices) to conduct their work—despite the long and prosperous history of such techniques within the scholar's own discipline. In addition, many SS and H scholars devote their time to the exploration and development of new methods and research approaches. They need room within the ethics framework to conduct this innovative work.

8b. Research with New Media

New media and evolving data collection sites and formats present many challenges for the conduct of social science and humanities research. These are not adequately addressed in the TCPS. For example, the TCPS does not address the unique problems that arise in Internet research, not the least of which is that the technology in that domain changes so rapidly that any effort to specify concrete requirements is likely to be obsolete by the time requirements are ratified and appear in print. Contributors of submissions noted two special problems that need to be considered in the context of the risks of Internet research: How can researchers and REBs assess the probability and magnitude of harm that may befall subjects in Internet research? And how can researchers effectively ameliorate any harm that does occur? Similar questions need to be raised about research involving other new media.

8c. Missing Fields of Study

Notwithstanding its diverse strategy for soliciting participation from members of Canada's diverse social science and humanities communities, SSHWC is concerned that at least one field of study is neither represented in the membership of SSHWC nor in the submissions SSHWC received. This area is the creation- or performance-based humanities (these include musicians, visual artists and performance artists). If PRE decides to renew and extend SSHWC's mandate, we suggest PRE consider adding a member to the Committeefrom that field.

Implications for Change
 - It is important that the TCPS be revised to accommodate a broader range of scholarly methods. We do not recommend that an inventory of methods now missing appear in the next version of the TCPS, since any list that purports to be exhaustive would be obsolete by the time the list is published. This would re-create the problem that exists now. However, such methods should be incorporated into discussions of the various ways that ethics principles might apply in divergent methods and methodological approaches. - The recent use of the Internet as a major source of primary social science research data is not adequately addressed in the TCPS. With such a void, REBs tend to fill in the ethics-approval procedure with inconsistent demands on researchers that show little awareness of the technology or netiquette, and/or the full range of data available to them. Notions such as harm and privacy vary considerably. Few REB members, and just as few researchers, have thought through the implications of the opening up of this social venue for research ethics considerations, and the way these considerations intersect with technological developments in the online community. - If the mandate of SSHWC is renewed for a second phase, we urge PRE to consider adding a creation- or performance-based researcher from the humanities (a such as a musician, visual artist or performance artist) to the committee.

IV. Conclusion

In general, criticisms of the TCPS as it is currently constructed centre around its failure to give voice to, and guidance for, the full spectrum of research. Providing that voice means acknowledging the huge differences between the clinical trial/experimental model that currently dominates the TCPS and the bulk of social science and humanities research on dimensions that have relevance to appropriate methods of ethics review.

Our report details some of those dimensions of difference, outlines ways the TCPS can be more responsive to SS and H researchers and those who participate in their research, and offers new approaches to ethics review that will better protect research participants, save the social sciences and humanities from becoming overly bureaucratized, and free REBs to spend more time on projects with greater potential for harm, which deserve their detailed consideration.

Appendix A

Members of the PRE
Social Sciences and Humanities Research Ethics Special
Working Committee, 2003

Dr. Will van den Hoonaard (Chair)
Department of Sociology
University of New Brunswick

Dr. Michelle McGinn
Faculty of Education
Brock University

Dr. Lisa Given
School of Library and Information Studies
University of Alberta

Dr. Patrick O'Neill
President
Canadian Psychological Association

Dr. Joseph Lévy
Département de sexologie
Université du Québec à Montréal

Dr. Ted Palys
School of Criminology
Simon Fraser University

Ex-Officio Members

Dr. Glenn Griener
National Council on Ethics in Human
Research (NCEHR) and
Department of Philosophy
University of Alberta

Dr. Keren Rice
SSHRC Standing Committee on
Ethics and Integrity and
Department of Linguistics
University of Toronto

Dr. Michael Owen
Canadian Federation for Humanities and Social
Sciences and
Director, Research Services
Brock University

Dr. Kathleen Oberle
CIHR Standing Committee on Ethics and
Faculty of Nursing
University of Calgary

Secretariat on Research Ethics
Ms Thérèse De Groote
Policy Analyst

Appendix B

PRE Consultation: Evolving the TCPS to Better Meet the Needs of Canada's Social Sciences and Humanities Research Communities

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Interagency Advisory Panel
on Research Ethics

Groupe consultatif interagences
en éthique de la recherche

Ottawa, Canada
K1A 1H5

To: Vice-Presidents, Research
         Deans of Graduate Studies, Education, Social Sciences and Humanities
         Heads of Departments
         Research Administrators
         Learned Societies
         Research Ethics Community

From: Interagency Advisory Panel on Research Ethics

Date: 1 August 2003

Subject: PRE Consultation of the Social Sciences and Humanities Research Community

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This is an open invitation to participate in a consultation on evolving the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS) to better meet the needs of Canada's Social Sciences and Humanities (SSH) Communities. The deadline for receiving submissions is **September 30, 2003**.

<div align="center">*******</div>

The Interagency Advisory Panel on Research Ethics[10] (PRE) is a body of external experts established in November 2001 by Canada's three Federal Granting Agencies (the Canadian Institutes of Health Research, the Natural Sciences and Engineering Research Council and the Social Sciences and Humanities Research Council), to support the development and evolution of their joint research ethics policy the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS).

When the TCPS was adopted in August 1998, the Agencies committed to keeping it a living, or "evolving", document in order to respond to new research developments and identified gaps in the Policy.

PRE has thus been created to advise the Agencies on the evolution, interpretation, implementation and educational needs of the TCPS. PRE's independent and multi-disciplinary advice is intended to promote high standards of ethical conduct, advance the protection of human research participants, and enhance accountability in research ethics.

In order to fulfill it mandate, the Interagency Advisory Panel on Research ethics (PRE) approved the creation of a PRE Social Sciences and Humanities Research Ethics Special Working Committee (SSHWC)[11] in November 2002**.** Following a public call for membership,[12] SSHWC held its inaugural meeting in May 2003. Its mandate is to provide advice and

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[10] www.pre.ethics.gc.ca
[11] www.pre.ethics.gc.ca/english/publicparticipation/callfornominations.cfm
[12] www.pre.ethics.gc.ca/english/newsandevents/whatsnew_sshwc_membership.cfm

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recommendations to PRE on (a) priorities and (b) methods and strategies for coherently addressing priority ethical issues in social sciences and humanities research involving human participants.

Consistent with PRE's basic processes, SSHWC's work is based on principles of transparency, community engagement and consultation. Thus far, the Committee has reviewed a wide range of materials and submissions that have been sent to PRE. It now continues to seek further contributions on issues that members of Canada's social sciences and humanities (SSH) communities believe require (re)-consideration in the *Tri-Council Policy Statement on the Ethical Conduct of Research Involving Humans* (TCPS). The material considered thus far suggests four basic categories of change to be addressed:

- **Core assumptions and paradigms of research** have been clearly identified as a class of concerns that must be addressed. A common critique is that the TCPS was originally based on more positivistic, experimental, and biomedical research models. This has created problems for some researchers who are guided by other paradigms of knowledge development.
  - o Examples of this include concerns that the TCPS should more clearly recognize diverse assumptions concerning the fundamental nature and intent of research (e.g., how research is defined; what is considered "legitimate" research; the inherently emergent and collaborative basis of some research approaches).

- The way that certain **core and guiding ethical principles** within the TCPS are applied in relation to the diversity of research that characterizes Canada's social sciences and humanities research communities has been questioned as well.
  - o For example, emphasis on the core concepts of "harm" and "protection" may require different consideration in more critical types of research, and/or completely miss concepts that are more highly valued in more collaborative research approaches, such as "relationship building."

- While a variety of **methods** are addressed and highlighted within the TCPS, many are not, thereby leaving REBs with little guidance regarding issues and "best practices" that characterize those approaches.
  - o Examples of methods that are not addressed or are insufficiently covered in the TCPS include autobiographical research, ethnography, participatory action research, historical research and text-based research.

- Finally, the TCPS has been critiqued for not providing sufficient guidance for a number of more **specific research techniques** and **sites** that are of particular relevance for Canada's social sciences and humanities communities.
  - o Examples include research involving human participants conducted on the Internet, and issues that arise with techniques such as snowball sampling.

The Committee welcomes your commentary on these and other issues that you believe are important for them to consider. If elaboration of the table below is a useful device, then please

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use it to convey your comments to the Committee. Please complete the information sheets and provide examples to illustrate your points, if necessary, or provide us with your comments on the back page of the table, whichever is more appropriate for you.

Please send completed information sheets to SSHWC: sshwc@pre.ethics.gc.ca or fax to (613) 996-7117 **by September 30, 2003**.

For further information about SSHWC, its mandate, and its place in Canada's evolving TCPS governance structure, please see www.pre.ethics.gc.ca.

In the coming months, SSHWC will likely consult further with the research community on social sciences and humanities issues. If you wish to participate, please write clearly your e-mail address below. Your e-mail will not be used for any purpose other than your participation in future consultations on issues related to the TCPS.

E-mail address (PLEASE PRINT):

_____

Please help us distribute this public call for comments as widely as possible by sharing it with others who may be interested in responding.

<div align="center">Thank you for your contribution.</div>

Coordinates: sshwc@pre.ethics.gc.ca or fax to (613) 996-7117

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PRE Consultation: Evolving the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS) to Better Meet the Needs of Canada's Social Sciences and Humanities Communities

You may also use the next page for comments if more appropriate for you.

Please send to: sshwc@pre.ethics.gc.ca or fax to (613) 996-7117 by **September 30, 2003.**

Core Assumptions and Paradigms of Research	
Application of Core and Guiding Ethical Principles	
Methods/ Methodologies	
Specific Research Techniques/Sites	
Other	

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PRE Consultation: Evolving the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS) to Better Meet the Needs of Canada's Social Sciences and Humanities (SSH) Communities

Please send to: sshwc@pre.ethics.gc.ca or fax to (613) 996-7117 by September **30, 2003.**

Comments

Appendix C

Implications for Change

1. How Extensive is the Need for Change in the TCPS to Save Social Sciences and Humanities?

- Deciding among the four alternatives described in section II is as much a policy question as a pragmatic one. SSHWC recommends that Option 1 (minor revisions to the existing TCPS, leaving its current structure intact) and Option 2 (a new chapter on ethics in the non-experimental social sciences and humanities) be rejected as insufficient. PRE should seriously consider Option 3 (a separate chapter and adapted processes of ethics review) and Option 4 (two completely separate ethics policies: one for the social sciences and humanities, and one for the biomedical/experimental sciences). (p.16)

2. Academic Freedom

- The TCPS should more explicitly affirm the necessity of academic freedom for a healthy research enterprise; remove reference to "responsibilities" that do not bear directly on the task of ethics review; state that it is unethical for REB members to infringe academic freedom; and indicate that REB decisions can be grieved using whatever mechanisms exist at the researcher's institution, when and if an REB strays beyond its mandated domain. (p. 19)

3. What Constitutes "Research"?

- The TCPS definition of research must recognize the diversity of ways that "research" is constituted in SS and H research communities. It should include discussion of how the ethics review process can be adapted in a manner that shows respect for traditions such as inductive and collaborative field-based approaches, or textual research, that are most compromised when expectations based on the narrower definition are imposed. (p. 20)

4. When is Someone a "Human Subject"?

- Further discussion is warranted in the TCPS regarding what being a "human subject" entails. We suggest that being a "human subject" implies a power differential between researcher and participant that arises from the nature of the relationship, conflict of interest, clear subject incapacity and/or opportunity for coercion. In the absence of such indicators, we suggest that PRE exempt such research from REB review, and consider social science- and humanities-appropriate mechanisms through which that exemption might occur. (p. 22)

5. Reconsidering "Minimal Risk"

- Designating a subset of studies "minimal risk" makes sense in areas such as biomedical research, where risk is always present and "minimal risk" studies are the exception. The concept is less useful when virtually all research is "minimal risk," as is more commonly the case in the social sciences and humanities. For social science and humanities ethics review, we suggest the TCPS instead focus on the notion of "identifiable harm." Only in instances where some clearly identifiable and significant harm is likely and requires mitigation should REBs be empowered to require alterations in research design. Development of an inventory of significant harms that warrant REB review, and minimal harms that do not warrant review, should also be considered. .(p. 23)

6. Re-considering Ethics Review

- PRE should consider establishing a "program review" model of research ethics approval in cases where research involves extensive, emergent and collaborative activities in the field. This could be done by allowing researchers to apply for a "research program" that would stay in effect for years at a time, and would specify a general set of parameters in which the research would operate. This program would have de facto REB approval until such time as the parameters changed. At that point, the researcher would prepare a new proposal or simply file an addendum. (p. 25)

- PRE should consider investigating "standard professional practice" across a range of social science and humanities disciplines with an eye toward developing a workable scheme of ethics review that operates within the TCPS framework, while more effectively balancing legitimate concerns regarding human subject protection with the right of researchers and citizens to interact free of regulation in a democratic society. (p. 26)

- Before requiring changes to a research plan, an REB should identify a concrete harm that has some likelihood of occurring, and has the onus of demonstrating that the ameliorative action it proposes has a better likelihood of alleviating that harm than the resolution offered by the researcher. (p. 26)

7. Course-based Research

- Although some institutions already incorporate these practices, we recommend PRE encourage greater standardization across institutions by articulating in-principle approval of the idea that responsibility for ethics review of all student course-based research projects (other than theses, dissertations and other one-on-one directed studies courses) be delegated to course instructors, given that such instructors are entrusted

in the academy with transmitting ethical standards in the context of generating discipline-specific knowledge. Institutions may require instructors to submit "course plans" to gain this delegation, and REBs can review these to satisfy themselves that course assignments are experience-appropriate and outline a set of standard operating procedures that are consistent with the TCPS and disciplinary standards. (p. 27)

8. Consent

▪ Default expectations for how and when consent will be negotiated, what information will be provided, and the need for signed consent forms should all be changed to recognize the impact that differences in relationships, research contexts, methods, and methodologies used by a broader variety of disciplines have on the desirability of particular approaches to ensuring consent. Researchers and REBs should attend to general principles concerning consent in the context of possible harm. (p. 29)

9. Privacy and Confidentiality

▪ The next version of the TCPS should give clearer direction to REBs and researchers engaged in field research regarding the variety of ways confidentiality issues can play out in various areas of research. (p. 30)

▪ Because of the crucial importance of confidentiality for certain kinds of research, we recommend that PRE investigate legal mechanisms used in other jurisdictions (such as confidentiality certificates and privacy certificates) for resolving the theoretical disjunction between statutory legal protections and researchers' ethical obligation to protect participants by keeping identifiable research information confidential. In the interim, we recommend that the TCPS provide information on how researchers who gather sensitive information that would harm participants if disclosed can maximize legal protections for participants through common law legal mechanisms such as the Wigmore criteria. (p. 31)

▪ The TCPS should incorporate a discussion of the problem of "heinous discovery" and of researchers' and REBs' responsibilities should such a situation arise. (p. 32)

10. Data Retention and Secondary Data Analysis

▪ The TCPS should acknowledge that issues of data retention are not as straightforward a matter as simply demarcating some Procrustean exposure date that is routinely applied. In the social sciences and humanities, many research programs do not have easily defined "start" and "end" dates, and researchers may have obligations to community collaborators and/or there may be other historical or research purposes served by data retention. Such matters

should be negotiated among researchers, participants, and, in some instances, the community. (p. 32)

11. International Issues

- The TCPS's new coverage regarding international issues should indicate that international involvements are more complex in the social sciences than the wording in Article 1.14 indicates. Discussion is warranted of what some of these complexities might involve, and how they have been resolved in various research traditions. (p. 33)

12. Gaps in Coverage

- It is important that the TCPS be revised to accommodate a broader range of scholarly methods. We do not recommend that an inventory of methods now missing appear in the next version of the TCPS, since any list that purports to be exhaustive would be obsolete by the time the list is published. This would re-create the problem that exists now. However, such methods should be incorporated into discussions of the various ways that ethics principles might apply in divergent methods and methodological approaches. (p. 35)

- The recent use of the Internet as a major source of primary social science research data is not adequately addressed in the TCPS. With such a void, REBs tend to fill in the ethics-approval procedure with inconsistent demands on researchers that show little awareness of the technology or netiquette, and/or the full range of data available to them. Notions such as harm and privacy vary considerably. Few REB members, and just as few researchers, have thought through the implications of the opening up of this social venue for research ethics considerations, and the way these considerations intersect with technological developments in the online community. (p. 35)

- If the mandate of SSHWC is renewed for a second phase, we urge PRE to consider adding a creation- or performance-based researcher from the humanities (such as a musician, visual artist or performance artist) to the committee. (p. 35)

Appendix D

**Identification of Social Sciences and Humanities
Research Ethics Issues Prepared for PRE's Social
Sciences and Humanities Research Ethics Special
Working Committee (SSHWC)**

Identification of Social Sciences and Humanities Research Ethics Issues Prepared for PRE's Social Sciences and Humanities Research Ethics Special Working Committee (SSHWC)

Revised November 18, 2003

What follows is a list of all the comments received between August 2003 and mid-October 2003 in response to the Social Sciences and Humanities Research Ethics Special Working Committee (SSHWC) Consultation of the Social Sciences and Humanities Research Community. A preliminary list was prepared for the SSHWC October meeting and updated, on request from the committee, to include issues identified during local consultations by SSHWC members and provided in written reports to SSHWC, as well as issues extracted from briefs and submissions received over the course of 2002 and 2003. The SSHWC felt that an integrated document would do justice to all the individuals who had taken time to convey their concerns and issues related to research ethics and the TCPS. The total number of submissions is 57, excluding the local SSHWC consultation reports. This list was assembled by Rainer Duschinsky, Student in Residence, and Thérèse De Groote, Policy Analyst, of the Secretariat on Research Ethics.

The comments have been divided into 27 categories: it should be noted that the order in which the categories appear is not reflective of their relative importance. Following each comment, in parenthesis, the comments have been classified. Wherever possible, comments have been classified as relating to one of the four "basic categories" of change identified by the Committeein its call for comments: S-1 refers to comments that address "Core assumptions and paradigms of research"; S-2 refers to comments that address "Core and guiding ethical principles"; S-3 refers to comments that address "Methods"; S-4 refers to comments that address "Specific research techniques". Where a comment was self-identified in the comment submission as belonging to one of the abovementioned categories, the initials "sid" follow the classification.

Although the majority of comments fell into the four basic categories of change, a significant minority of comments did not: these comments have also been categorized. The majority of the "other" comments were procedural—a "P" is used to represent issues classified as procedural.

Following the statement of the issues are bullets with further descriptions of the problem. These descriptions, taken directly from the e-mails and other communications that were received, provide greater detail about the problem and/or change the submitter wished to see addressed. Where possible, we refer to TCPS articles, pages or sections. These references are, however, not exhaustive and do not always cross-reference. It is hoped these references will help the reader to understand the present TCPS guidelines vis-à-vis the issues that they follow; in a few cases, it is believed that the TCPS already provides the answer to the concern that the issue raises.

The number in square brackets directly above each issue identifies the particular submission from which the issue is drawn. Reports on local consultation are identified with the reference "L" in brackets.

List of Issues

1. THE "ONE-SIZE-FITS-ALL" MODEL

[L4-1] There is a need to move away from the present one-size-fits-all model.

[4.01]   The TCPS, in spite of the best efforts of the three councils and the people who framed it, strongly represents a specific model of scientific research as "standard" and defines other models as "exceptions. " (S-1)

[4.03]   The assumption that ethical research is "scientific" is problematic. (S-1)
- The vast area of qualitative ethnographic research that does not directly address social policy, institutions, or public figures lies in the shadows.

[4.04]   I invite the panel to rethink the operant principle that one set of rules fits all. (S-1)
- I am recommending, correspondingly, that there be a basic set of standard guidelines that pertains to everyone, and then special sections.

[4.05]   There is a lack of consideration in the TCPS of non-experimental forms of research. (S-1)
- Recommendation: a separate section of the TCPS devoted to non-experimental forms of research, particularly focusing on the social sciences and humanities.
- This section must begin by recognizing and emphasizing the legitimacy of these kinds of research.
- The section must recognize that in much ethnographic and participatory research, questions to be studied generally emerge in the course of the research.

[4.08]   The trans-disciplinary approach of the TCPS is flawed. (S-1)
- Les chercheurs constatent que c'est clairement le modèle biomédical et expérimental qui a influencée le modèle normatif présenté dans l'*Énoncé*.

[4.09]   The approach of the TCPS, although claiming to be trans-disciplinary, is clearly biomedical. (S-1)

[4.11]   The homogeneous discipline ethics application of the TCPS is not legitimate. (S-1)
- Is it reasonable to expect that "the fundamental ethical issues and principles in research involving human subjects are common across the social sciences and humanities, the natural sciences and engineering, and the health sciences"(p. i.2, TCPS)?
- At how many universities is there a common committee, the members of which review the ethics of research regardless of whether the research is in the social sciences and humanities, natural sciences and engineering, or the health sciences?

[4.17]   The TCPS needs to include a set of core assumptions and paradigms of research that are inclusive of the underlying assumptions premised in post-structuralist, post-modern, post-colonial, trans-national, post-Marxist, indigenous, critical and culturally sensitive research. (S-1)

[4.20]   Need for a set of discipline-specific ethics review forms that (a) set out principles of good practice relevant to the disciplines concerned [(S-3)] and (b) pose a series of questions that are pertinent to the type of research that a person in that discipline might be undertaking. (S-3)
- Respect arises from having forms and procedures that actually recognize the character of the research being undertaken.

  ➢ *Art. 3.1, 3.2*

[4.22] The existence of a core assumption, based on the biomedical model, that all research is funded research. (S-1, sid)

[4.25] Need for TCPS to specify that REBs should respect Professional Codes of Ethics and REB cannot change standardized tests. (S-2, S-3)

[4.26] Recognition should be provided in the TCPS, reflected in REB decisions, that designs differ for different disciplines. (S-2, sid)

[4.28] Need for REBs to be willing to accept a research proposal based on a constructivist model: with a research question that is refined in reaction to the object of the study. (S-3)

[4.28] Positivist/biomedical model. Researcher objectivity understood in terms of neutrality is very uncertain, and not necessarily to be wished for. (S-1, sid)
- The researcher can, and potentially must also [in research on the mistreatment of children and on domestic violence], go beyond the descriptive and quantitative analysis of the facts. To deny the subject's tremendous closeness to his/her subject matter would impoverish the process without establishing any real distance. . . In this regard, the phenomenological approach and constructivist approaches in general are credited with including and using the participants' interpretations.

[4.29] The TCPS should put emphasis less on the uniformity of ethical standards than on the diversity of ethical predicaments faced. (S-1)

[4.29] Disciplines that use ethnographic and field methods (in differing ways, anthropology, human geography, political science, sociology, communications studies) should not be made to accede to the biomedical/behavioural research model. (P)

[note:. Many observations and suggestions vis-à-vis diverse qualitative and field-based strategies of research follow.]

[4.32] The medical model is being misapplied. (S-1)
- As we see it, many if not most of the problems were due to the attempt to create a single set of guidelines for all three granting agencies. This may have some veneer of efficiency in the eyes of bureaucrats, but in practice it has not worked. For one thing, what this blending has done is to allow the discussion of research safety to be completely dominated by what is a very limited biomedical model, the "clinical trials" paradigm. [underlining in original]

[4.32] The criterion for important research has been redefined. (S-1)
- Due to the acceptance of the assumption that the biomedical model provides a good prototype, all research areas have become implicitly burdened with the notion that the only good research is that which provides improved (medical) "treatment" (and the sooner the better).

  ➢ *i.6—"Benefit" concept*

[4.34] The need for separate REBs for SSH. (S-1)

[4.36] A single code of ethics is inappropriate for all disciplines. (S-1)
- The body best suited/equipped to regulate ethical practices is the discipline itself.
- The current code is geared to the traditional, hypothetical-deductive research design in which the parameters of the research are known in advance. Risks can be easily identified

in such projects and "true" informed consent is possible. . . The existing code essentially discourages many non-traditional research methods.

[4.38]   The fact that different disciplines have different needs should be recognized in the TCPS. (S-1)
- Hard-and-fast ruling across all SSHRC disciplines would be, in my opinion, disastrous.

[4.39]   Although the TCPS is seen to be comprehensive, it is at the expense of humanities researchers, for whom many of the issues and emphases do not apply. (S-1, sid)

[4.44]   The current code does not recognize types of research work other than those based upon the "biomedical" model, and for that reason cannot accommodate them without distorting them beyond recognition. (S-1, sid)
- Biomedical research is clearly the paradigm for the existing ethics code.

[4.45]   The biomedical model does not always fit the type of research and related ethical concerns on our campus. (S-1, sid)
- The guidelines and assumptions should reflect other models of research.

[4.46]   Validity of different methods of social science research. (S-3, sid)

[4.48]   The scope of research contained under the current Tri-Council framework appears to draw primarily from those disciplines engaged in experimental or quasi-experimental design research. (S-1, sid)

[4.48]   The guiding ethical principles have a thematic orientation toward the sciences rather than the social sciences and humanities. (S-2, sid)

[4.48]   The TCPS gestures towards the complexity of research but because of the dominance of a science-based view, does not always give voice to the contradictions and tensions inherent in conducting research ethically because science-based contexts may be narrower. (S-4, sid)

[4.50]   The medical model: The TCPS is based on an experimental research method that assumes that researchers will know what their research outcomes may be. (S-1, sid)
- The ethical practices it recommends depend on researchers' ability to predict research outcomes or to know what results they anticipate before they begin the fieldwork. Historical research does not predict its outcomes at the outset. Looking for evidence to prove a predetermined hypothesis may deter historians from analyzing the evidence that does not support the researcher's hypothesis.

[4.50]   Balancing harms and benefits in the TCPS is not properly tailored to the requirements of SSH research. (S-1, sid)
- The harms and risks in the TCPS and in university ethics review processes is based on a medical research model. . . . The ethical review process should be modified so that it is tailored to the specific research methods of social sciences and humanities research.

[4.51]   The notion of "harm" employed by REBs (which is drawn, at least partially if not fully, from the TCPS) is too stringent. (S-2)
- The harms that are apt to be produced by social scientific research are rarely of the same magnitude as those that medical science has produced.

[4.57]   The concept of risk needs to be redefined away from medical conceptions of accountability. (S-2)
- We do not need a "one-size-fits-all" policy.

[4.58]   The TCPS needs to move away from a biomedical based paradigm of what is research on/with human subjects. (S-1)
- It would seem that perhaps two different sets of regulations and committees treating applications Ethics in Research on Human Subjects would work better, one for scientific, biomedical research, and one for social sciences and humanities research.

2. GENERAL versus SPECIFIC NATURE OF TCPS

[L4-5]   The TCPS should be a guide with general principals, rather than a repertoire of specific situations. (S-1)

[4.15]   Keep the present "generality" of the TCPS.
- I would not like to see a very specific set of rules and regulations come out of the working committee. The diversity of research methods requires a general policy statement that allows latitude when applied.

[4.41]   The TCPS should not set out specific requirements for research techniques like ethnography and snowballing. (S-3/S-4)
- There should be no specific requirements/procedures attached to the paradigms mentioned in the substantive category "Core Assumptions and Paradigms of Research." (S-1, sid)
- Nature of TCPS guidelines versus rigorous rules: The TCPS should not set out specific requirements for research techniques like ethnography and snowballing. I hope recommendations remain at a fairly general level, as approaches to consider rather than as limits on using specific methods or techniques. ...This could reduce researchers' choices of methodologies and infringe on academic freedom. (S-3)

[4.49]   The TCPS in its present form is too general. (S-1, sid)
- There should be rules or more specific examples for the implementation of rules, providing a better context to guide REB members.

3. GAPS IN THE TCPS: TYPES OF RESEARCH

[L1]   The public policy exemption of Article 1.1(c) has been interpreted too narrowly. (S-2)
- The political scientists who attended my open session view this as no exemption at all, and encouraged us to re-open this issue and to recommend that the exemption should be a broad one.

[L3]   Researchers from health studies and community and regional planning were among the most vocal in complaining about the lack of exemption for research where public figures and agency employees, that is, adult professionals, are being interviewed. (S-2)

[4.02]   The TCPS completely ignores participant observation, the key method of research in sociocultural anthropology and increasingly in some other fields. (S-4)
- The basic driving assumptions of the entire TCPS seem to be that research takes place in enclosed spaces (such as in university laboratories) as part of discrete projects.
- Fieldwork that takes place in living and complex communities rarely occurs in discrete time blocks.

[4.03]   The major gap is that no section is devoted specifically to qualitative and ethnographic research. (S-3)

- Many of the problems REBs have in applying the TCPS to qualitative research could be alleviated simply by writing a section devoted to this type of research.

[4.08]   An essential element missing in the TCPS is ethically correct practices for anthropology. (S-3)

[4.11]   The present content of the TCPS fails to adequately reflect the context and nature of research undertaken in the field of education. (S-2, S-3)
- It is recommended that the Canadian Society for the Study of Education:
  1. develop a statement of the ethical norms and practices of educational research; and
  2. recommend to the three councils that this statement be incorporated in the Tri-Council policy on the ethical conduct of educational research.

[4.37]   Collaborative research is under-considered. (S-2, sid)

[4.37]   Community–university partnership research / participatory research is not adequately considered in the TCPS. (S-1, sid)

[4.39]   Issues have arisen in the areas of ethnography and anthropological research at our university whereby the TCPS was severely lacking in guidance. (S-3, sid)

[4.40]   Guidelines for non-experimental forms of research are needed. (S-1)
- [University X] recommends a separate section of the policy devoted to non-experimental forms of research.

[4.40]   Naturalistic observation. (S-4)
- Clear guidelines should be provided for purely naturalistic observational research.

  ➢ *Art. 2.3, Naturalistic Observation*

[4.42]   Ethical issues around fieldwork need to be reconsidered in the TCPS. (S-2, S-3)
- Fieldwork is inherently a social activity . . . "In the field, one becomes part of a social network in the speech community under investigation, and thus this type of research necessarily involves as much personal and social effort as it does linguistic 'brain work'." (Dimmendaal 2001: 55)
- It becomes increasingly clear that Eurocentric ideas of knowledge and of gaining knowledge are not necessarily the same as many Indigenous ones.

[4.44]   Participant observation research is not accommodated by the current core assumption, and core and guiding ethical principles. (S-3, sid)

[4.45]   Issues and best practices around participatory action research would be helpful. (S-3, sid)

[4.46]   The TCPS does not deal with the issues of intellectual property rights of communities versus individuals. (S-2)
- This makes work with many cultures challenging—particularly with First Nations groups where rights to knowledge may be owned by families or groups rather than by individuals.

[4.46]   Collaborative research is particularly poorly served by the existing TCPS. (S-4, sid)

[4.47]   Collaborative research is particularly poorly served by the existing TCPS. (S-3, sid)

- The TCPS fails to realize the dialogue involved in collaborative research, and the changing nature of ethical practices over time.

[4.55] Linguistic Field Work: Such research endeavours should be assumed to follow a standard protocol and only deviations from that protocol should receive closer scrutiny and be required to make an individual ethics application. (S-3)
- At no point is the linguist ever interested in specific content, such as personal or cultural issues. The goal of the linguist is to gain an understanding of the structure of the grammar and sound systems of the language.

4. GENERAL CRITIQUE OF THE REVIEW PROCESS (Section 1: Ethics Review)

[L1] The need for researchers to identify research subjects before ethics review is problematic in regard to "emergent" research in the more qualitative vein. (S-1)

[L3] The ethics review thus far under the TCPS has far more to do with "review" than "ethics." (S-1)

[L3] There is frustration with the length of time it takes to prepare proposals and have them go through the review process. (P)

[L3] Concerns were expressed regarding many of the fundamental assumptions of ethics review under the TCPS. (S-1)
- The review process was considered comparable to that of establishing a "license" to go out and do research. One researcher wondered aloud about the logic of training researchers in their area of specialty for a decade and have them come out with a PhD, only to assume they are unethical at graduation, and require them to ask for permission for each project they undertake.

[L3] Complaints about the absence of any rational debate about the costs and benefits of the creation of a huge new bureaucracy for the purpose of ethics review. (S-1)

[L4-2] In research for which part is "contracted-out," the result is a doubling in the number of forms that must be filled out by subjects. (S-3)

[L4-3] Our institution does not believe that the centralization of ethical review of student projects is a good thing. (S-3)

[4.01] The TCPS seems to assume that it is possible in all cases to identify a researcher for each project, but this is not always easily done, especially in large projects in the humanities and social sciences. (S-1)
- In a time of emphasis on collaboration and teamwork, the councils should strive for some clearer statement of responsibility than is presently in Section G of the TCPS

[4.03] The issue/assumption that the same sorts of harms/benefit assessments can be applied across research disciplines and paradigms, and the related issue of criteria to be used by REBs in allocating proposals to full, expedited, and departmental review needs rethinking. (S-1)

[4.04] The requirement not to begin research until approval is granted from the REB is problematic. (P)
- In the case of participatory research in particular, the idea for the research is often generated from the people who will become the participants.

[4.04]   The ethical review process has been framed as if researchers know what they are going to do before they begin. (S-2)

- In all emergent design research, the researcher discovers where to go next as the researcher proceeds.

[4.08]   The review process leads to bureaucratization, when what is needed in the anthropological field are suppleness and flexibility. (S-2)

[4.09]   The ethical and procedural elements of the TCPS have led to a bureaucratization that seems to be poisoning researchers and research directors. (S-2)

- The lack of trust and respect, and even scorn towards researchers' capacity for ethical judgement, is evident in the Statement, which is entirely focused on control, surveillance, and discipline.
- Other weaknesses involve the very mission of the Statement, which is oriented toward the protection of human subjects to the detriment of reflection on the moral issues connected with the practice of social science in today's world.

[4.10]   Long review process of the research ethics board. (P)

[4.19]   The current process is not sustainable due to the extremely onerous demands on REBs. (P)

- Solutions Proposed:
  1. Tri-Council funding for teaching releases for REB members (analogous to Release Time Stipends(RTSs) available for SSHRC Standard Research Grants);
  2. A more distributed model (effectively, academic unit-based committees)—more committees but smaller workload.

  ➢ *Art. 1.4(b)*

[4.24]   The process is very slow. (P)

- Professors avoid the committee like the plague because it is so time-consuming to read the files.

[4.24]   There is a general dislike of the ethics review procedure.

- It is onerous paperwork, and from their [colleagues'] standpoint, appears to have little purpose.

[4.32]   There is no objective evidence for the effectiveness of, or need for, REBs. (Implementation)

- "Respect, beneficence and justice" are commendable aspirations, but if self-defined by an ethics reviewer, unmonitored and undocumented, then they become an open-ended license for at least manipulating the research agenda by irrelevant ideological dictates, and quite possibly explicit censorship.
- It is, therefore, quite remarkable that REBs apparently are exempt, self-policing bodies. It is an extreme of irony that for a service directed toward research, there are no data (research) on the effectiveness of any aspect of the enterprise!
- In fact, the failure to document both the *necessity* and *effectiveness* of REBs is irresponsible and unethical in itself. The present plan for running REBs would not survive submission to a peer-review journal (and certainly not to an REB!).

[4.32]   The researcher is being treated as though he or she is a nuisance. (S-1)

- Communications and review mechanisms now operate on the presumption that the researcher is unethical and must prove innocence. Not only do researchers not feel

interested, the sentiment that their involvement is not wanted, and even that the researcher is the problem, is quite clear. As sad as that is, there is every reason to believe that the relationship will deteriorate even further in the future.

- Given the lack of consequences to the institutions for such abusive treatment of researchers [two specific "witch-hunt" cases are discussed], there is no reason to expect such malicious witch-hunts to diminish in number or severity in the future. To the extent that (a) we continue to permit the fuzzy goal state (ethics and social engineering instead of safety) and (b) fail to document effectiveness, it seems likely that in the future there will be more such incidents rather than fewer. The most parsimonious and most accurate description of these activities is "censorship."

[4.32] The existence of REBs themselves sets up many double standards. (S-1)

- Why is it that academics must be so restricted in terms of human interaction, compared with others? An anthropologist wanting to conduct interviews in Central America spent two years getting clearance, whereas CBC newsreader Peter Mansbridge could be there in 24 hours or less.

[4.34] Differences between the TCPS guidelines and the manner in which they are being applied at University of X. (P)

[Note: Many examples are provided in a comparison of the issues according to the university's guidelines and the TCPS.]

[4.34] Undergraduate research review process needs relaxing. (P)

[4.36] There is a problem with the consistency of judgments across REBs. (P)

- Often REBs appear to be exceeding their authority and mandate, becoming over zealous and/or picky, questioning details or issues not really germane to the proposed study.

[4.37] The ethics process is overly dominated by researchers, when in reality they have no monopoly on ethics. (S-2)

[4.41] Ethical policy should have a more positive thrust. (S-2, sid)

- The suggested change in core ethical principles is welcome. The Tri-Council statement focuses on risk and potential harm, a negative approach that sometimes implies a distrust of researchers.

[4.46] There is a need to promote research as a positive activity with value for Canadian society. (S-4, sid)

- The vast majority of people enjoy their interactions with researchers, and yet REB application forms and the TCP [sic] are couched in terms of risks and possible negative impacts, coercion/exploitation.

[4.46] As it presently stands, the TCPS constrains research and rarely works to engender discussions of ethical research practices. (S-2)

- The TCPS should be a document that requires practitioners of all sciences to think about their ethical principles and to question their research practices. Instead, it has become a prescriptive document that defines norms and acceptable boundaries for research . . . . It is seen by many as the imposition of yet another layer of bureaucracy.

[4.47] The TCPS places the onus for flexibility on local REBs, yet, paradoxically, in many situations it appears that local REBs across the country have simply fallen back on the TCPS and refused to accept the responsibility necessary to allow for flexibility. (S-other, sid)

- The TCPS should be a document that requires practitioners of all disciplines to think about their ethical principles and to question their research practices. Instead, it has become a prescriptive document that defines norms and acceptable boundaries for research.

[4.48] The TCPS should be concerned with compliance with ethics policies and not with the administration of ethics policies. (S-2)

[4.53] There is a need for consistency of interpretation and implementation of the guidelines. (P)

[4.57] What sense does it make to turn social science into a highly regulated research profession when journalists and market surveyors can ask the same questions (or more) without ethical regulation? (S-2)

[4.58] The process (application for ethics approval; implementation of written agreements/permissions from the artists or other participants concerned) is framed in too-negative, legally intimidating terms.
(S-1)

5. IMPLEMENTATION

[4.41] Communication of change to the TCPS: changes should be made only infrequently. (General)
- While the idea of a living or evolving document may be good in principle, if it is too lively and evolves frequently, this can create confusion and difficulties for a Research Ethics Board that is required to continually change standards and procedures.

[4.46] The TCPS should require renewal of ethical certificates only once every three years. (P)
- The three major Canadian government funding bodies work on a three-year cycle.

6. SCOPE AND LEVEL OF REB REVIEW (Section 1: Ethics Review)

A) *Minimal Risk / Proportional Review / Expedited Review*

[4.38] The TCPS should explore the possibility of expedited review for more spontaneous research methods; for example, "talking to people about their jobs." (P)

[4.41] Research projects that pose minimal risk do not need the intensive preparation and scrutiny presently required by the TCPS. (P-proportionate review)

[4.49] The guiding principle of "level of risk" is badly applied. (S-2, sid)
- Most, if not all, of the questions that social science specialists may ask participants are less risky than the 6 o'clock news, to which our fellow citizens and theirfamilies are nevertheless exposed.

[4.52] Clarification on procedures for "expedited review." (P)

[4.53] The conditions in which a proposal receives expedited review, or is deemed of minimal risk, need to be clarified. (S-1)

B) *Students*

[4.41] The TCPS requirements in the area of undergraduate studies should be relaxed. (S-3; P)

- Some instructors have changed or eliminated certain types of assignments because it would be too time-consuming to make ethics applications for all the possible projects.

[4.52] Is the REB responsible to review all graduate student research projects involving human subjects, including course work related research? (P)

C) *Scope*

[4.22] Uneven application of what is "research involving human subjects" in different REBs.

[4.51] The scope of research ethics proposals that need to be treated by REBs is overly broad—quite simply, too much is presently under an obligation to submit. (S-2)

7. MONITORING OF ONGOING RESEARCH (Section 1: Ethics Review)

[L4-3] The present system for monitoring ongoing research is an example of a biomedical model being applied to all disciplines. (S-1)
- Most research projects conducted by researchers involve no or very few risks for the subjects.
- In four years, experience has shown us that modifications submitted by researchers for approval purposes do not require ongoing surveillance from the Committee.

[4.01] It is much less clear what the monitoring referred to in section 1.2 means in regard to the humanities and social sciences, than in regard to experimental research. (S-3)

[4.30] There is a need for monitoring of ongoing research (P). Specifically, it should be tied to peer review and student supervision. (S-2)

[4.38] There is a need for REBs to ensure/confirm compliance of research proposals that are approved. (P)

8. REB MEMBERSHIP REQUIREMENTS (Section 1: Ethics Review)

[L1] REBs do not have the membership to judge a variety of projects. They are required to have two scholars who work with human subjects; no two scholars can cover the broad array of methods and techniques in use in the social sciences and humanities.

[L2] Researchers from more qualitative traditions are a minority in the social science community who are often underrepresented or not represented at all on REBs.

[L3] Concerns were raised about limits to expertise that REB members seemed unwilling to acknowledge.

[4.04] It should be stipulated that at least two members of the REB should have expertise in qualitative research. (S-2)

[4.25] Clarification in the TCPS of research experience required for members. (P)
- I was wondering if you could clarify the TCPS. Perhaps specify that members should at least have five to ten years of research experience and published [*sic*] and five to ten years of teaching experience.

  ➢ *Art. 1.3, Membership of REBs*

[4.25] Need for research and publication experience of REB chairs. (P)

[4.25] Need for Research Officers to have research experience and have been published. (P)

[4.28] The need for at least one, if not two, researchers who have considerable social science experience in all REBs. (P)

[4.28] Put social science methodology manuals at the disposition of all REB members. (P)

[4.38] REB membership: all those deciding ethics matters should be active researchers. (P)

9. SCHOLARLY VALIDITY (Section 1: Ethics Review)

[4.10] REBs acting on quality concerns, not ethical concerns. (S-2)
- Research Ethics Board has been acting as academic research police.

> ➢ *Art. 1.5, Scholarly Review*

[4.26] REBs should not comment if they do not know the discipline or design of research proposals very well. (S-3, sid)

> ➢ *Art. 1.3, 1.5—Membership and Scholarly Review of REB*

[4.32] Scholarly review of research projects as it is presently taking place is resulting in REBs evaluating research outcomes, which they should not be doing. (S-2)
- "Social desirability" is an *ideological* matter. It has nothing to do with public safety. Extrapolated uncritically to SSH, this concept is now undermining the epistemological integrity of research efforts in SSH. REBs have become involved in trying to evaluate research outcomes, which they should not be doing.

10. REB ACCOUNTABILITY (Section 1: Ethics Review)

[L3] Several researchers expressed concern that REBs were straying beyond their mandate and should exercise restraint. (S-2)
- Liability-based criteria are worrisome when REBs lose sight of the fact that their role is to protect research participants, and start making decisions that seem to be for protecting universities and researchers *from* participants.

[L4-4] We sometimes have the impression that REBs are more concerned with protecting institutions than participants.

[4.10] Accountability of REBs to researchers. (P)
- They have to be accountable, given that their decisions have significant implications for researchers' careers.

> ➢ *Article 1.9, Decision-making*

[4.25] Implementation of a system for the filing of grievances by researchers, against REBs. (P)

[4.26] There should be a code of ethics for how the REB treats their researchers. (P)

11. EDUCATIONAL AND FACILITATION ROLE (Section 1: Ethics Review)

[L4-1] Researchers are not sufficiently aware of how the law influences the way in which they do research, especially in regard to confidentiality of information gathered. (S-2)

[4.10] REBs' role as being to facilitate research, not to constrain it. (P)

> ➤ *Art. 1.9, Decision-making*

[4.26] If research covers all aspects stated in the application of core and guiding principles, then the research should be approved. (S-1, sid)

12. REB PROCEDURES (Section 1: Ethics Review)

[L3] Some REBs require more concrete information than many researchers—particularly field researchers following collaborative or emergent epistemologies—are willing and able, for reasons of epistemological choice, to give them. (P)

[4.40] A need for regular REB meetings. (P)
- These discussions raise the challenges associated with applying the policy to such diverse research methodologies. These discussions have helped identify the recommendations we are making.

[4.40] A need for open meetings for researchers. (P)

[4.41] The TCPS should not be mandatory; rather, REBs should be allowed to use it as a guideline. (P)
- Some of the difficulties our REB has had emerge from the mandatory nature of the TCPS.

[4.52] Which parts of the REB review process can be done "electronically" and which parts require face-to-face meetings? (P)

[4.52] How should one respond to projects where some data collection has already been done? Are there guidelines for this kind of "retroactive approval"? (P)

13. RESEARCH "SUBJECTS" (Section 1: Ethics Review)

[L1] Too little attention is paid to views of research participants regarding their rights and interests. (S-2)

[4.01] The present TCPS seems to be written from a point of view in which the "subject" of research is the same as the "participant". (S-1)
- What protection can—or should—be provided for other people whom the interviewee may choose (or be asked) to mention?

[4.06] There is a need for an amendment, or explicit interpretation of the guidelines, that would allow for basic consultation tasks with no conceivable harm to the "subject" to be exempt from external review, in a manner that would nevertheless preserve the integrity of the review process for those kinds of research to which it is intended to apply. (S-2)

[4.14] The implication by the TCPS that all subjects of research are potentially vulnerable is unrealistic in regard to "powerful" subjects. (S-2)

- What is missing from the ethics guidelines is a clear statement that social science researchers have a right and an obligation to engage in critical scrutiny of the way power is wielded, and that, in many cases, their legitimate primary concern may be, not any vulnerabilities of their subjects, but the vulnerabilities of those who are affected by the decisions their subjects make.

[4.18] Use of term "subject" versus other possibility to refer to individual involved in the research (S-1)

- In what follows I use the terms "interviewee," "informants" or "respondents" where the current Ethics Policy Statement uses the term "subjects." . . . . In all of these cases, the interviewee is a fully competent adult . . . . In these circumstances, the terminology, suggesting that either the interviewee is subordinate to the researcher or is subject to an experimental procedure, is inappropriate.

[4.18] Problem of terminology due to the use of words such as "procedures" and "experiments" denoting biomedical or other experimental research where the word "research" would be sufficient. (S-3)

[4.22] Existence of a core assumption that who is and who is not a "research subject" is easily ascertained. A related core assumption is that only "research subjects" require protection. (S–1, sid)

- For example, in biographical research involving the use of diaries and other unpublished documents, while the subject of the biography may be a research subject, individuals mentioned in a diary, who may or may not be living and may or may not be vulnerable to harm, do not appear to be "research subjects."

[4.37] The use of the term "research subjects" in the TCPS is not appropriate because it implies passivity, and further implies that researchers [*sic*?] are the agents of the research process. (S-1, sid)

[4.52] Who is considered to be a "subject" or research participant? (S-2)

14. DEFINITION OF RESEARCH (Section 1: Ethics Review)

[4.01] A strict application of the present TCPS definition of research might rule out a good deal of work that is termed "research" in the social sciences and humanities. (S-2)

[4.15] Clarification of commentary subsequent to article 1.1, on page 1.2 of TCPS: "REB review is generally not required for research involving public policy issues." (S-2)

- A lot of research on public policy involves surveys, interviews, focus groups, etc., which are the same as other human-participant research that must be reviewed. The phrase needs to be clarified.

[4.37] Definition of research. (S-1, sid)

- When does information gathering become systematic?
- What is the distinction between consulting and research?

[4.38] Definition of research. (S-1)

- Oddly, the TCPS seems to consider this an easy question.

[4.39] Definition of research. (S-1, sid)

- A clear definition of "research" is needed, as opposed to those practices deemed standard "profession activities." For example, there are conflicting views in the area of commerce and marketing.
- Further clarification on what constitutes program evaluation and when ethical approval is required is needed.

[4.39] Guidelines on the criteria for a "program of research" could be [his wording] developed. (S-4)
- Some of the behavioural science research projects involve a series of smaller studies/experiments. Instead of reviewing each individual project, the REB gives approval for a "Program of Research."

[4.41] Definition of research. (S-1)
- Role of researcher/advisor in external research with community group. One of the major difficulties I experienced as Chair of the REB was deciding the limits of our mandate; that is, what are the limits of what is meant by university research.

[4.47] Definition of research. (S-1, sid)

[4.48] Definition of research. (S-1, sid)
- Read against the work of philosophers such as Poovey or von Fleck, the term "fact" itself is contentious.
- Additionally missing from the definition is the whole question of the manner in which the "results" of the research are represented.

[4.52] Definition of research. (S-1)
- Some artistic endeavours include human subjects or participants. Are these projects subject to ethics review? If not, who will safeguard their interests when participating in these reviews?

[4.52] What is understood to be "professional practice" and therefore not subject to review under the TCPS? (S-4)

15. MINIMAL RISK (Section 1: Ethics Review)

[L1] The TCPS needs to make a stronger statement that REBs are not to concern themselves with adequacy of method unless the minimal risk threshold is crossed. (S-2)

[L1] It is hard to know what constitutes minimal risk in the social sciences and the humanities. (S-2)

[4.30] In social science and humanities proposals, which deal with interpersonal relationships at the individual and group levels, an evaluation of the degree of harm and protection to interpersonal relationships should be included in research proposals. (S—3)

[4.32] Zero risk has become the accepted norm for assessing research proposals. (S-2)
- The expectation of "zero risk" has replaced the notion of "everyday risk" in ethics reviews. The question was never to be "could something go wrong?" but whether the likelihood of adverse consequences would exceed normal life, everyday risk.
- Ironically, the distinction between these two notions, zero versus everyday risk, is actually still quite clear in medical research, where the concept of "side effects" is well accepted by researchers, subjects and review boards. Yet REBs in SSH now turn back

proposals in pursuit of the fiction of "zero risk." That is, REBs seem to require that absolutely no psychological discomfort could possibly occur.

> ➢ *Art. 1.6, Proportionate Approach to Ethics Assessment*

[4.44] There is consistent misinterpretation by REBs of the guiding ethical principles: respect for free and informed consent, minimizing risk, and respecting confidentiality.
- Perfectly innocuous projects have been aborted by repeated referrals from local REBs when there is no potential for danger to research subjects

[4.53] The term "everyday" requires definition. (S-4)
- The term should be added to the Guiding Ethical Principles.

> ➢ *Art. 1.6, Minimal Risk and Proportionate Review*

16. FREE AND INFORMED CONSENT (Section 2: Free and Informed Consent)

A) *Definition of Informed Consent*

[4.51] The way in which informed consent is defined in the TCPS is problematic. (S-2)

B) *Of Children*

> ➢ *Art. 2.5—2.7, Competence*

[4.08] The age of 18 as the frontier for requiring parental consent is sometimes inappropriate. (S-2)
- Traiter en mineure incapable de décider pour elle-même une jeune mère de 17 ans, ce n'est pas la respecter comme personne pleine et entière, ce n'est donc pas la « protéger », en particulier contre les stéréotypes qui nuisent déjà à son estime d'elle-même.

[4.11] Free and informed consent in regard to schoolchildren. Third party consent, informed and freely given, should be sufficient for research with minimal risk to children in school. Parent/guardian consent, informed and freely given, be required for participation in research with risk above the threshold of minimal risk. (S-2)

[4.33] Referring to children as "incompetent individuals" (such as in Article 2.6) does not afford the dignity and respect for uniqueness that each child brings to the domain of new, innovative and creative research. (S-1)

[4.39] Parental consent requirements are not appropriate or obtainable in some behavioural science research projects. (S-2, sid)
- It would be useful to have guidelines where parental consent can be waived.
- Assent guidelines need to be expanded and developed: for example, a child in high school gives assent to participate in the survey although the parent did not give consent.

> ➢ *Art. 2.7, Ascent and Dissent*

C) *Signed Consent Forms*

[L1]   Researchers want clearer indications in the TCPS that the informed consent process need not always be written (or require a signature), and that imposing such a requirement, in some circumstances, may actually endanger participants. (S-2)

[L4-1] The situations where written consent is not required need to be expanded and developed.

[L4-4] The need for gaining written consent from a family member in the aftermath of a suicide is detrimental to gaining their confidence.

[4.02] The assumption that written consent is preferable to consent obtained orally appears to us to be designed to protect institutions rather than research participants. (S-2)

[4.03] The issue/assumption that free and informed consent means written consent fits well with biomedical and health research, but fits poorly with qualitative social research. (S-1)

[4.08] The policy requiring written consent prior to interviews is overly rigid. (S-1)

[4.09] The idea of asking for consent from persons who one is going to publicly criticize seems impossible or counterproductive to many researchers. (S-2)

[4.09] The idea of having to sign a consent form with each new "subject" seems absurd. (S-1)
- Pour beaucoup de personnes, le fait de devoir signer un document est en soi difficile et même compromettant.

[4.15] The TCPS might take a broader approach to the need for signed consent forms. (S-2)
- There are many situations in research where signed consent is normally not obtained. I can think of mailed surveys and Internet research, where signed forms are not used.

> ➤ *Art. 2.1(b)—P. 2.1, Written Consent Culturally Unacceptable*
> ➤ *Art. 3.1—3.2, Accessing Private Information: Personal interviews, Surveys, Questionnaires and Collection Data*

[4.18] Complexity of the present informed consent process, including but not limited to obtaining written consent, particularly in cultures where such formalities are foreign. (S-2)

[4.29] Potential marginalization of groups/individuals: problems in gaining written consent in populations that are non-literate, have reason to be suspicious of attempts to make them sign documents, or might fear incrimination. (S-2)

> ➤ *Art 2.1(b), (c)*

[4.35] The present rules for obtaining informed consent are culturally biased. (S-1, S-2, sid)
- The message that was conveyed to me by the application form, guideline and colleagues' experiences was that the standard procedure of obtaining informed consent is by using formal and written consent forms, complete with participants' signatures, and that other ways of obtaining informed consent are automatically scrutinized and deemed suspicious. The onus is on the applicant to satisfy reviewers as to why the "standard procedure" is not followed.
- It is important to understand and grapple with cultural biases in research practice norm established in a Western context.

> ➢ *Art. 1.14, Other Countries/Jurisdictions; Art. 2.4, Informing Potential Subjects; Section 6: Research with Aboriginal Peoples*

[4.38] The TCPS, presently, is biased towards written consent. (S-2)

[4.40] Due to illiteracy or cultural norms of trust in relationships, it may not be appropriate to have written consent.

[4.46] There is a need for more leeway when it comes to the issue of informed consent. (S-3, sid)
- Oral consent is frequently more comfortable to those engaged in a conversation than signed papers.

D) *(Marginalized) Groups and Collectivities*

[4.01] Issues surrounding consent in regards to "ethnographic" approach to research.
- Can one member's lack of consent overrule the desires of other members of the group and make a study ethically impossible?

[4.01] Action research presents particular problems with regard to a blurring between the role of researcher and participant.
- The ethical problems arise if they [members of the community] call upon a professional to provide advice and research expertise to assist them in their objective.

[4.04] In regard to communities, particularly marginalized ones, researchers should be required to conceptualize and conduct the research with the group as partners, to involve the group in the design of the project, to make efforts to represent the viewpoints of as many different segments of the group as possible, etc.

[4.08] Individual consent does not necessarily ensure group/community protection.

[4.09] Individual consent does not necessarily ensure group/community protection.

[4.37] The need to give voice to marginalized groups is not reflected in the TCPS. (S-1, sid)

> ➢ *Section 5, Inclusion in Research*

[4.40] Collectivities: Important issues relating to communities (other than Aboriginal communities) are not addressed in the TCPS. (S-2)
- Examples include new immigrant women, elderly in a seniors home, populations with specific health issues, religious groups, workers in a subordinate employment situation. . . For example: who owns the data after it is collected, who speaks for the community, how do we determine initial and ongoing consent of individuals and community leaders?

[4.43] Researchers who engage in lesbian, gay, bisexual, transsexual, transgender, two-spirited, queer and questioning (LGBT) research must indicate how they are accountable to the LGBT communities in their research methodologies, representation of LGBT communities, and dissemination of findings. (S-2, sid).

[4.43] Research on the health of LGBT people must include input, voice and visibility, and enhance more equitable participation of diverse members of these communities in order to promote the self-determination of these communities. (S-1, sid)

[4.46] The TCPS does not deal with the ethical issues of returning knowledge to communities and individuals. (S-2)

> ➢ *Section 6, Research with Aboriginal Peoples*

[4.55] There is a need for recognition in the TCPS of the difficulties that can be inherent to the process of gaining "community consent." (S-2)
- The issue of community approval varies across communities with some groups wanting approval of all research on their language, while other groups are actively seeking research partners in efforts to preserve their language, and do not view language data as being the property of the collective.
- It should not be assumed that each community will have the same viewpoint, even within a single cultural group.

[4.57] Informed consent: there needs to be more sensitivity to the differences among social groups and social contexts and the ways in which informal consent (for example) operates in this context. (S-2)
- Many research subjects have less than high school education—we need better mechanisms for allowing their participation.

E) *Critique of an "Over-" Consent Environment*

[4.21] Concept of harm and vulnerability of subjects is overrated in survey research: current ethics practices at Canadian universities result in limitations being placed on survey researchers that have the effect of seriously depressing response rates. (S-2)
- Students are not illiterate peasants . . . . They can be made aware that they don't have to respond without confronting them with various forms of legalese that will have the likely effect of making them suspicious of the survey . . . . The arbitrary requirements of various ethics committees not only have the effect of depressing response rates, they also increase research costs.

> ➢ *Art. 3.1–3.2, Personal Interviews, Surveys, Questionnaires and Data Collection*

F) *Informed Consent: Vulnerable Versus Non-vulnerable Participants ("Elites")*

> ➢ *Art. 1.1(c), Research Requiring Ethics Review; Art 3.1–3.2, Personal Information, Surveys, Questionnaires and Data Collection*

[4.20] Subject vulnerability: "Confidentiality of Information / Protection of Sources from Harm" of elites. (S-1, S-2)
- A standard form of political research is elite interviewing. . . . What are the relevant ethical issues involved in such interview? What forms of consent are required? What are the accepted research protocols? This sort of information should be on the form (for the benefit of the REB, as well as the researchers). If it were, the attention of researchers would be focused on the relevant questions, not on issues that have nothing to do with the form of research in question.

[4.22] Standard Informed Consent from "Equals/Superiors." (S–2, sid)
- Advising judges and lawyers as to the meaning of informed consent, their freedom to refuse an interview and their freedom to terminate an interview at any time might imply the researcher thinks the judge or lawyer to be interviewed is incompetent because they do not know these things. [Author's note: In reality, the judge/lawyer will, unless they are incompetent, know enough to understand the reasons behind such enquiries.]

[4.24] Vulnerability of subjects: problem with the need for political scientists to take a host of precautions when they are interviewing "powerful people". (S-2)

- The bulk of their interviews are with officials who can turn them down, dance around, and generally cause all sorts of problems if anything in an interview displeases them. In other words, it is not an equal playing field. The interviewee is in control.

[4.27] Current Informed Consent rules are overly burdensome: there is a need for a distinction to be made between vulnerable and non-vulnerable populations. (S–4, S-2)

- I conduct research with the cooperation of professional accountants and accounting firms . . . . The firms vet researchers [*sic*] proposals quite carefully and are quite amused to say the least about the long information forms and the requirement for signed consent.
- The current set of ethics rules in Canada assumes implicitly that all subject populations need to be protected by the "mommie" research ethics professionals via mountains of paperwork and extensive documentation.

[4.54] Living artists, writers and performers should be regarded as public figures, like politicians, therefore exempting research on these people from the very stringent approval process. (S-2)

G) *Informed Consent as a Process and Relationship between Researchers and Participants*

[4.37] Free and informed consent needs to be reconsidered, given the increasingly emergent and collaborative nature of research (that is research designs that evolve based on community participation). (S-2, sid)

[4.40] The policy assumes that consent occurs at a single point: before the interview or when the subject is enrolled in a clinical trial. However, in long-term ethnographic research, for example, there is not a clear start and end date. Often there are repeated visits over several years or even decades, during which trust is developed. (S-2)

[4.46] The TCPS should be concerned with the principle of establishing trust relationships rather than with the process of documenting them. (S-1, sid)

[4.53] Informed consent: the guidelines need to accommodate more equable subject–investigator relationships. (S-1)

- In naturalistic inquiry research, subjects may want and request to be identified, and sometimes even authorship, on collaborative work.

[4.55] Consent in fieldwork: where the collection of data is mutually beneficial and collaborative, the formal and asymmetrical nature of the consent process is likely to alter the perception of equality in the relationship. (S-2)

- One possibility in this instance is that a consent document could be drafted jointly between the linguist and collaborating speaker(s), outlining the nature of the relationship.
- Potential harm is virtually never a possibility.

[4.55] Consent through tape-recording versus written consent. (S-2)

[4.58] The present requirements vis-à-vis informed consent are often detrimental to the researcher/informant relationship. (S-2)

- To obtain their [informants'/subjects'] permission verbally, while leaving with them a letter introducing the research, the project, and outlining their rights, is the system that works the best, in my experience.

H) *Specific Issues or Recommendations*

[4.05]   TCPS must recognize the greater complexity of the issue of informed consent in ethnographic research than in clinical or other experimental research. (S-4)

[4.18]   The "Letter of Initial Contact" / Advance notification requirement should be rephrased as preferred rather than obligatory. (S–3)
- It is impossible to make advance contact with individuals whom one wishes to interview in societies that have neither listing of addresses nor current telephone books . . . . In such societies, the researcher depends on interpreters and advisors to find individuals who are willing to be interviewed, and the interview necessarily occurs without earlier formalities.

[4.18]   Information obtained without an interview or other formal procedure. (S-4)
- An anthropologist or sociologist who wants to understand a culture rarely depends on formal interviews.
- There are also occasions where permission to observe, participate, and record information can only be obtained from leaders or other persons in charge of groups.

[4.18]   Information freely provided by an interested party. (S-2)

[4.23]   Issues around deception and debriefing. Incorrectness of the basic assumption (continuously growing in acceptance) that any deception at all of any kind is necessarily harmful to the participant, and thus participants should never be told anything other than the strict truth about the purposes of the research in which they are participating. (S-1, S-2)
- There are questions that we need to study for the public benefit that require that participants be naïve while being studied.
- For example, if I were studying factors that influence eating behaviour, and I wanted to see if obese and normal-weight individuals act differently under the same conditions, . . . should I tell participants this afterward? If I tell them this and they realize that they were being studied because they are fat, is this beneficial to them?

> ➢ *Art 2.1, p.2.3—Partial Disclosure and Debriefing*

[4.38]   The current requirements for informed consent are making it difficult to attract research subjects. (S-2)

[4.48]   With its emphasis on "prior informed consent," the policy sidesteps issues of representation of the data collected. (S-1, sid)

17. PRIVACY / CONFIDENTIALITY (Section 3: Privacy and Confidentiality)

A) *Confidentiality*

[L1]   The TCPS sections on confidentiality need revising to better reflect the variety of ways that confidentiality issues can play out in the field research context, and to take into account the recent literature regarding the law and ethics of research confidentiality. (S-2)

[L3]   Several researchers expressed concern about current provisions in the TCPS regarding confidentiality because they do not trust the REB to maintain confidentiality as thoroughly and carefully as the researchers do. (S-1)

[L3]   REBs who require evidence of parent organization assent, or who require the researcher to create a paper trail (for example, by requiring written and signed informed consent) can endanger the very research participants they are supposed to protect. (S-4)

[L4-1]   Chapter 3 of the TCPS should provide standards in regard to privacy, confidentiality and the protection of subject responses in regards to electronic information. (S-2).

[4.15]   In Section 3 of the TCPS, the phrase "identifiable personal information" is used frequently, but what that information entails is left open to interpretation.

> ➢ *p. 3.2: Definition of identifiable personal information*

[4.30]   Confidentiality versus informant recognition: research participants should not be able to have their name revealed/shared if they so choose. (S-2)
- It's been my experience that in some forms of qualitative research, confidentiality is somehow confused or conflated with the idea of relationship building and empowerment . . . . if empowerment is the purpose and intention of the research, for and with the participants, are there other ways of achieving that?
- As researchers we can't know for sure what the consequences of revealing the participants [*sic*] identities will have on them in the future, and we can't ensure that it won't lead to any negative consequences.

[4.30]   Whether harm is likely to occur or not, confidentiality should be maintained unless there is benefit for not maintaining confidentiality—in which case, the participant has to go through the process of informed consent. (S-3)

[4.30]   Guidance in the TCPS with regards to using the "snowball" technique for obtaining research participants—issue of confidentiality of information gathered. (S-4)
- It would be unethical for me to ask volunteer participants to reveal the names of other students or supervisors that they knew of who had experienced conflict in their relationship.

[4.39]   Guidance is needed to address issues such as confidentiality and anonymity in focus groups. (S-3, S-4, sid)
- Focus groups are often used in behavioural sciences research.

[4.44]   Understanding definition of public domain: the TCPS incorrectly asserts that any interaction with an individual constitutes an extraction of personal information (such as participant observation research). (S-2, sid)
- By imposing this methodological and ontological individualism on all human subjects research, however, the Tri-Council policy attacks the foundation of all social and cultural research.

> ➢ *Art. 1.1 (c), Research Requiring Ethics Review; Art. 3.1-3.2, Personal Interviews, Surveys, Questionnaires and Data Collection*

[4.50]   There is an over-insistence on anonymity. (S-2)
- [Due to enforced anonymity of academic sources,] academic claims are inadvertently losing their epistemological weight and critical edge.

[4.50]   There are problems with the TCPS emphasis on privacy and confidentiality vis-à-vis social historian research goals. (S-2, sid)

[Note: recommendations for changes to the consent process are attached.]

- The emphasis on privacy and confidentiality in the TCPS contradicts social historians' research goals. In many studies, historians prefer to identify informants as a way to highlight the contributions that ordinary people have made to social and political life.

[4.53] Sections 3.2 and 3.3 need to be clarified: confidentiality of interviews. (S-4)
- Qualitative researchers publish verbatim text from the interviews, and as such cannot assure confidentiality. Qualitative researchers can, however, provide anonymity for participants.

B) *Privacy Legislation*

[4.22] Multiple privacy "requirements" of TCPS and federal and provincial privacy legislation. (S—Other)
- The TCPS was drafted prior to the full effects of federal and provincial privacy legislation coming into force. Privacy legislation, outside the framework of the TCPS and uncoordinated with it, imposes a multiplicity of regulations and varying standards on the same piece of research in some cases.

[4.52] How will the upcoming changes to PIPEDA impact REB review? (S)

C) *Specific Records*

[4.18] Publication/Recording of data. (S-4)
- The ethics of research extend to the forms of publication. For example, it is unethical to film persons without their knowledge. However, there are occasions when that proviso cannot and should not be maintained.

[4.30] Confidentiality of data from videos and photographs: there should be a requirement of justification vis-à-vis value added with regard to the use of these tools in public presentations. (S-4)

[4.38] How does one deal with anonymity or confidentiality when using new technologies, such as audiotape or videotape? (S-4)
- The concept of public space has also been transformed. As soon as anyone walks into the Internet Studio on the second floor of Social Sciences, they are being beamed worldwide to researchers who are studying their interactions in virtual space.

[4.29] The assurance of the confidentiality of data or the anonymity of subjects cannot always be reconciled with the demand of some institutions or Band Councils that original materials (such as tapes or transcripts) be housed in a local archive or site. (S-2)

18. SECONDARY DATA ANALYSIS (Section 3: Privacy and Confidentiality)

[4.13] Public use of "sample files" (anonymous data). (S-4)

> ➢ *Art 3.3-3.6—Secondary Use of Data*

[4.13] Concern over the possible introduction of new, stringent ethical legislation requiring the gaining of signed agreement by researchers from respondents, even for the purposes of conducting secondary data analyses, such as PIPEDA. (S-4)

- Stringent legislative restrictions on the use of secondary data and administrative records stripped of all individual identifying information would cripple researchers' ability to make significant breakthroughs regarding social, economic, demographic and health problems facing the population.

[4.13] Administrative records: definition. (S-3)

[4.53] The privacy statement makes the false assumption that data, once collected, is available publicly.
(S-4)
- Confidentiality and anonymity may be maintained by the researchers during processes of analysis, and the protection of confidentiality and anonymity may occur at the time of publication and presentation.

[4.59] Third-party access to contact information should be less restricted. (S-4)
- Without using *active* third-party contact methods, etiological studies of many diseases (that is, those without disease registries) are extraordinarily difficult to conduct.
- My own experience is that most people are delighted to participate in health research, and are shocked to know that ethics rules and government agencies might stand in the way of this.

19. DATA RETENTION

[4.05] Ethnographic projects data should not be subject to the requirement of many REBs that data, such as tape recordings, videos and interview transcripts, be destroyed after the project has ended. (S-2)

[4.40] It should not be assumed that data should be destroyed after a research project. (S-2)
- REBs should consider whether data should be destroyed or appropriately archived, and who should decide how and where this is done.

[4.41] There is an inconsistency between SSHRC initiatives on ethics and on archiving. (S-2)
- I suggest that the consultation address the two issues of ethical standards and archiving simultaneously, so that these standards coincide rather than being at cross-purposes to each other.
- Archiving and secondary data use could potentially benefit Canadian society in the future, and at little cost.

[4.50] The TCPS needs to modify the guidelines about secondary use of data to recognize that one of the goals of oral history it to generate historical evidence for future research. (S-4, sid).
- The policy recommends that researchers assure research participants that the data will be destroyed once the project is complete. Historians prefer not to destroy data. Rather, interviews are deposited in a public archive for future use. However, as mentioned above, research projects about sensitive issues may require the destruction of interview tapes.

[4.55] Issues surrounding data retention: for example how are materials collected through tape recordings, etc., to be used and preserved? (S-3)

[4.57] Concerns that research documents (such as audiotapes) be destroyed. (S-2)
- This will change the long-term plans, [sic] as they may apply to research projects.

20. RESEARCH METHOD/METHODOLOGIES

[4.14] Researchers should be allowed to use whatever research method works best for them. (S-4)

- My experience, and that of many other researchers I know, is that electronic or tape recordings waste a great deal of time (and money if they must be transcribed) without producing more accurate results. More seriously, they introduce a "chill". Many officials who are entirely willing to speak frankly to a note-taking researcher will become uncommunicative at the click of a recorder.
- Other researchers may reach a different conclusion about the recording of interviews, but neither they nor I should be prevented from using the research methods that work best for them.

> ➤ *Art. 3.1- 3.2: Personal Interviews, Surveys, Questionnaires, Collection of Data*

[4.16] PRE and SSH research are heavily skewed towards Eurocentric research methods. TCPS should develop and empower Indigenous methodologies, pedagogies and languages. (S-3, sid)

- One of the priorities needing to be greatly strengthened is First Nations' methodologies developed from their languages, rather than from Eurocentric languages and scholarship. This goes to the issue of stabilizing language loss and creating integrity in research involving First Nations.
- Indigenous knowledge is a transdisciplinary study rather than interdisciplinary or disciplinary study. It is a complete knowledge system with its own concepts of epistemology, philosophy, humanities and arts.

> ➤ *Section 6: Research with Aboriginal Peoples*

[4.28] Positivist/biomedical model. Researcher objectivity understood in terms of neutrality is very uncertain, and not necessarily to be wished for. (S-1, sid)

- The researcher can, and potentially must also [in research on the mistreatment of children and on domestic violence], go beyond the descriptive and quantitative analysis of the facts. To deny the subject's tremendous closeness to his/her subject matter would impoverish the process without establishing any real distance. . . In this regard, the phenomenological approach and constructivist approaches in general are credited with including and using the participants' interpretations.

[4.48] The TCPS needs to recognize the validity of social sciences methods of collection. (S-3, sid)

21. OBTAINING REB REVIEW IN OTHER COUNTRIES/JURISDICTIONS (Section 1: Ethics Review)

[4.15] With respect to article 1.14, it is often very difficult to obtain ethics review from an REB in the other country or jurisdiction. (Procedures)

> ➤ *Art 1.14, REB Approval in Other Countries or Jurisdictions*

[4.52] What are the expectations of the REB to make sure that "international projects" have passed due diligence in terms of local REB requirements? (P)

[4.55] It is presently unclear which jurisdiction is paramount when a researcher and subject (for example research by phone/e-mail) are in different geographical locations. (P)

22. RESEARCH SITES

[4.15] Internet research. (s-4)
- While most of the same issues apply here as in other human-participant research, there are a few unique issues (for example, gaining informed consent and the Internet) that the TCPS could address.

  ➤ *Art. 3.1, Personal Interviews*

[4.39] Clear ethical guidelines are required for Internet-mediated research. (S-4, sid)

[4.39] Clear ethical guidelines are required for telephone surveys. (S-4, sid)

23. RESEARCH WITH ABORIGINAL PEOPLES (Section 6: Research with Aboriginal Peoples)

(A) *Consultation*

[4.16] Urging of a good-faith effort to consult with First Nations and develop high standards of ethical conduct, advance the protection of First Nations research participants, and enhance accountability in research law and ethics toward First Nations subjects. (P-general)

[4.16] Before any research can be decided to be conducted with First Nations communities or peoples, they must be involved and their view taken seriously. Before any results of the research are made available to communities and government decision-makers, the involved First Nations must sanction it. (S—2)

[4.16] Most, if not all, research with First Nations persons would benefit immensely from partnerships with Elders and knowledge keepers of the First Nations of Canada. (S-3)

(B) *General*

[4.16] Understand that Aboriginal jurisprudence and law of the First Nations shape the ethical consideration as constitutional law rights. (P-general)
- Canadian courts have held that agencies of the federal government are required to consult with First Nations on any policy or activity that would interfere with their constitutional rights, their existing Aboriginal or treaty rights. They have created a constitutional standard of "good-faith" consultations that controls the activities of TCPS, even though it operates at arm's length from the research. This standard is the highest standard in Canadian law and should inform consultation activities of the TCPS.
- The duty of consultation requires Canada and third parties to provide a Treaty or Aboriginal First Nation that may be affected by government legislation or a decision with "full information" on the proposed legislation or decision.

[4.31] The need for improved Indigenous Community Research Guidelines. (S-2)

[Note: The guidelines developed through a consultation between representatives of University X and several local Indigenous community members have been provided as an example.]

[4.39] There has to be further and complete development of section 6.0, Research Involving Aboriginal Peoples. (S-2, sid)

- Comprehension and understanding of Aboriginal culture needs to be adhered to, which may conflict with core ethical principles, such as privacy, confidentiality and anonymity. For example, an Aboriginal participant does not want to be given a number identifier to participate in a research project, which is a psychological survey study. The participant wants to take ownership of he says [*sic*] and wants his voice to be heard.

[4.45] Further information and guidance regarding Aboriginal perspectives on ethical research would be appreciated. (S-Other, sid)

[4.50] The TCPS "good practices for research involving Aboriginal people," which promote partnerships between scholars and Aboriginal communities, may limit historical research on controversial subjects within First Nations communities. (S-2, sid)
- Approval from chief and council may hinder historical research on divisive issues in First Nations communities.

24. MULTI-CENTRED / MULTI-SITE RESEARCH (Section 1: Ethics Review)

[L1] There is a lack of consistency between different REBs. (P)

[L3] Researchers believe REBs are inconsistent, and take this as evidence that "ethics review" is more a function of the personalities of REB members than of any systematic and thoughtful consideration of ethics. (P)
- Multi-site studies are the favourite evidence here, where REBs at different institutions are said to respond completely differently to the same proposal, often going so far as to "require" conflicting and contradictory procedures across sites.

[L4-3] Point G in the TCPS, which requires that multi-centre research must be examined by each respective REB, slows down and complicates matters a great deal. (S-2)

[4.21] Multi-site research / Multi-centred research: lack of consistency. If one university approves a research plan, that should be sufficient. (P)
- Each committee insists on putting its particular stamp on the research process [leading to inefficiency, greater cost, loss of time].

> ➢ *Section G: Multicentred Research, and Art 1.14, Other Countries and Jurisdictions*

[4.22] Multi-Centred Research: ethics review processes of organizations not bound by the TCPS. (TCPS Structure)
- Who does the review first, the TCPS-governed university or the other organization? (P)

[4.27] Need for mutual recognition of REB decisions between universities. (P)
- The lack of recognition by one university of another's ethics board approval is a joke.
- I have even had co-authors withdraw from projects so that they would not hold their co-investigators up, as their ethics process would take too long.

[4.36] Need for reciprocity between REBs. (P)

[4.37] Partnerships between community organizations / private sector: lack of clarity on which academic standards of ethics apply. (S-1, sid)

[4.50] University REBs interpret the TCPS differently. (P)

- This is particularly frustrating for graduate students. Ethical practices approved by one university for MA research have been questioned when the student seeks ethical approval for PhD research.
- These inconsistencies reinforce the prevailing notion that the ethical review process is a hoop-jumping exercise rather than a process that compels researchers to think seriously about important ethical issues.

[4.57] The present process of needing approval from REBs at each university for multi-site research is redundant and a loss of time. (P)

25. ACADEMIC FREEDOM AND TCPS (Context of an Ethics Framework)

[L2] The present system of REB review is endangering academic freedom. (S-2)

[L3] One of the more general concerns expressed by researchers from several different departments involved the prospective death of academic freedom and the narrowing of the research enterprise for reasons that have nothing to do with ethics, and everything to do with image maintenance and liability management. (S-2)

[4.22] Drawbacks of the downloading of regulation of research involving human subjects to universities.
- Universities' indirect costs of research are substantially increased. University's fear of liability and university counsel's desire to protect their client, the university, from any and all possible exposure to liability can have a chilling effect on the type of research that gets done.

[4.32] The future of academic research is threatened by the present REB SSH evaluation system. (S-2)
- As it becomes increasingly difficult to do SSH research from an academic platform, with more and more regulations of undocumented validity, it seems reasonable to expect a faculty selection process to occur. Ironically, the tactic of being obliged to deal with minor and apparently meaningless demands is a key part of the process whereby prison guards establish authority over prisoners, such as in Zimbardo's infamous prison experiment. Some faculty may capitulate and carry on, but it would not be surprising that many senior faculty may move their efforts re scholarship to consulting activity, books, or other venues that avoid confronting unwarranted constraints on their intellectual inquiries.

[4.34] Principles of academic freedom are not properly addressed in the TCPS. (S-1)
- I am also thinking about the principles of collegiality and academic freedom, which, when this policy was implemented in an atmosphere of urgency and the threat of funding cuts by the granting Council, were quite poorly addressed.

[4.43] Systems of knowledge production: research, education, and policy making must take into account both the implicit and explicit dynamics which influence how these domains interact to privilege some knowledge over others and hence which diminish the potential contributions and capacity building of research communities in social sciences and humanities and allied research communities. (S-1, sid).

[4.43] Ethical considerations in terms of which researchers are involved need to be considered. (S-2, sid)

[4.43] Historically, research on LGBT issues has been stigmatized and implicitly discouraged in academic settings. (S-2, sid)

[4.57] The degree to which ethics committees have a chilling effect on research is worrisome. (P)

26. TCPS STRUCTURE

 [4.11] TCPS: structure.
- Why does the document contain a separate and "special" section for clinical trials and three separate sections for human genetic research: human gametes, embryos or foetuses, and human tissue?
- Why are there no special sections or articles for other minorities, such as special needs students and students from countries whose culture is different than ours, and for men?

[4.30] Regarding the four categories of substantive issues, which SSHWC drew to the attention of contributors: all of these issues appear to be related to the difference between quantitative and qualitative research paradigms. Perhaps these issues could be addressed collectively through the inclusion of a separate section for qualitative research. (TCPS Structure).

[4.53] The TCPS needs an index. (P)

27. MISCELLANEOUS

 [L2] Does the TCPS apply to the federal government? (S-1)
- Consider the situation where a researcher has affirmed and embraced her obligations to research participants, and the REB has agreed with her stance and approved her proposal, while federal government agency is requiring her to violate TCPS provisions regarding conflict of interest and confidentiality.

[L2] Internet-based social research and REB competence? (S-4)
- What struck the researcher most about his exchange was how prepared the REB was to make decisions about what he should and shouldn't do, even though, in his view, they knew so little about the Internet and the power and limits of the technology.

[L2] Are there *a priori* constraints on what SSHWC can recommend? (S-4)
- In representing our work to the participants in these discussions, I told them—or wanted to tell them—that we have not precluded any possibilities.

[L4-1] A section on the rights and responsibilities of partner organizations should be introduced into the TCPS. (S-2)

[L4-3] Researchers should be able to have access to an advance on grant money *before* REB approval. (P)

[4.01] It is unclear from the language of the TCPS whether self-supported research, *pro bono* research, and research undertaken independently on contract is subject to REB review. (S-3)
- At present there is no way to ensure that research that is not financially managed by the university is submitted to the ICEHR [REB] in the planning stage. The language of the TCPS should be made clear.

[4.04] One of the principles that the ethics review process is founded on is the principle of respect. Yet there is no clear language requirement in line with this principle. (S)

- I am recommending that there be a clear statement that, except insofar as they are doing research into such use of language, it is unethical for researchers to employ language that is sexist, heterosexist, racist, anti-Semitic, ablist or oppressive to transgendered persons.

[4.06]   The majority of student research at the undergraduate level in language and linguistics, which does not involve risk to participants, should be exempt from ethics review. (S-1)
- In the vast majority of cases, this research consists of nothing more than asking people's opinions about linguistic usage: how is a certain word pronounced, is a certain sentence correct, etc. It is impossible to construe this sort of research as involving any risk to the participants.

[4.08]   The "moral approach" of the TCPS does not take into account the context in which research takes place, particularly international research. (S-1)
- Guided by a framework defined pratically exclusively by an experimental/hypothetical and deductive research model, the ethics framework proposed by the TCPS remains very silent in regards to the practice of anthropology in the context of violent nationalism or repression: "who do we have an ethical obligation towards if national governments are increasingly repressive to their own citizens?"

[4.25]   Need for TCPS to specify that REBs should respect professional codes of ethics and REB cannot change standardized tests. (S-2, S-3)

[4.30]   Consequences of participants' withdrawal from research by simply stopping to co-operate. (S)

[4.38]   Dual Role: conflict of interest implicit in using individuals for "multiple roles." (S-2)

[4.38]   There is a need for all supervisors to upgrade their knowledge regarding ethics and to speak directly with the REB in order to sort out differences. (P)

[4.43]   Heterosexism (as well as biphobia and transphobia) in research and other institutional domains influences what research questions are asked, by whom, and with what consequences? (S-4, sid)