

November 14, 2007

To: Sponsors' Table Secretariat ([secretariat@hrppc-pphrc.ca](mailto:secretariat@hrppc-pphrc.ca))

Re: Experts' Committee Report *Moving Ahead*

From: Social Sciences and Humanities Working Committee Members

The Social Sciences and Humanities Working Committee welcomes the opportunity to respond to *Moving Ahead: Draft Report of the Experts Committee for Human Research Participant Protection in Canada*. As Social Sciences, Humanities and Fine Arts scholars concerned with ethics we have undertaken extensive research and consultation in our communities which has led to several reports and recommendations for improving Canada's ethics system [e.g. 2004's *Giving Voice to the Spectrum (GVS)* and 2007's *Qualitative Research in the Context of the TCPS (QR)*]. We represent hundreds of social sciences and humanities (SSH) scholars from across Canada with whom we have consulted over the past four years in expressing our grave concerns with the *Moving Ahead* document and asking that the Sponsors' Table quash the recommendations made in this report. In particular, we would like to make the following points:

1. The problems and concerns with the current ethics system (e.g., make-up of REBs; problems qualitative researchers have faced with existing policy/procedures; the need for better education on research ethics) were identified and articulated by SSHWC in 2003-2004 in *GVS*. Over the past four years, through ongoing public consultation, we have worked to address these concerns and make recommendations for solving these problems. Although we know that many scholars (and qualitative researchers, in particular) have had problems under the existing system (and while the Experts Panel cites our findings in their report), we do not believe that the structure proposed in *Moving Ahead* presents a viable solution to these problems. Further, we are concerned with the diminishing tone used in this report with respect to the needs and beliefs of the SSH community as reflected in our work. For example, on page 9, the report notes that "some members of the social science and humanities communities have objected to having *what they regard* (emphasis added) as a biomedical system of oversight applied to their work". We have collected hundreds of submissions from SSH scholars in Canada that document the imposition of a biomedical framework on their work and their objections to this imposition. Other individuals and groups outside of the SSH community have also identified and objected to the biomedical framing of current approaches to research ethics governance. To diminish their experiences in this report is an affront to these scholars and further reflects the normalized practices of the biomedical ethics environment that SSH scholars have themselves identified as inappropriate and damaging. One need only examine the make-up of the Experts Panel itself to see that this report does not speak to, or for, SSH scholars in Canada; the vast majority of members are from the medical and natural sciences, leaving SSH scholars woefully under-represented, particularly in the area of qualitative research. The language, tone and examples used here reinforce the

biomedical hegemony that we first identified in *GVS*, presenting yet another model that will adversely affect SSH research in Canada, if implemented.

2. There is no “status quo” related to ethics practices in Canada, as Question #2 (page 3) presumes. The ethics system in Canada has been improving since we first published *GVS* in 2004 and our committee has been moving ahead with further recommendations for change. Our *QR* discussion paper, for example, responds to a significant gap in the current TCPS and has proven to be a useful resource for scholars in this country and worldwide. We have worked closely with scholars and research participants in this country to identify problems and to make recommendations for solutions to the Panel on Research Ethics (PRE). Whether PRE will show the wisdom to adopt these changes is another matter, but after four years of hard work, our recommendations (and those coming from PRE’s other working committees), will be ready for implementation in 2008. It would be premature to remove the existing structure and start over; rather, the time is right to provide the support necessary to implement the recommendations that SSWHC will be making to PRE for implementation next year. Creating an entirely new governance structure will only slow the evolution of ethics in this country.
3. We were troubled, in particular, by the fundamental fallacy presented in this document; namely, that the structure presented here will solve the problems that exist in our current system. There is no evidence provided here that the proposed structure will solve these problems. Rather, knowing the ethics issues and the SSH community as well as we do, we believe that this structure will actually entrench – rather than reverse – the problems that social sciences and humanities (SSH) scholars face in this country. The proposed model (as reflected, too, in the make-up of the Experts panel itself) reflects the biomedical model that currently governs research ethics policy and practices in Canada and offers a minor variant of the U.S. model that SSH researchers in the U.S. have expressed grave concerns about for more than a decade. We have worked tirelessly to identify the problems with the imposition of just this type of biomedical ethics model on the SSH in Canada, so we are saddened and frustrated that this is the model presented here for “solving” our existing problems.
4. One illustration of this biomedical imperialism is reflected in the call for accreditation in this report. While we do believe that improved measures of accountability are required to provide a balance for REB power in order to better protect academic freedom, to date there has been no call within the SSH community for accreditation. To the contrary; there are many reasons *not* to implement such a system, due to the harm that it would impose on the SSH community. It has come to our attention, through our extensive consultations, that where accredited systems have been implemented in the United States (for example), SSH scholars have faced more methodological persecution and inappropriate governance of their work. IRBs in these systems have imposed rigid, inflexible processes that do not account for research ethics context (of the community, of particular disciplines, etc.), which is particularly damaging to SSH

research. This type of rigid, inflexible model is exactly the opposite of what we would recommend for Canadian researchers to reflect the diversity of methodological and epistemological approaches in our country. As we noted in our *GVS* report, “one size does not fit all” researchers. While the accreditation system outlined by the experts panel may be appropriate for multi-site biomedical and clinical research that crosses international boundaries and involves very clear steps and procedures that are highly regulated and universally adopted, imposing a normalized accreditation system that dictates uniformity and universality will do great harm to SSH scholars and their research participants. If Canada is to be a leader in ethics policy and practice in the world, we need to *avoid* accreditation, not embrace it. Accreditation has not created a fruitful environment elsewhere and is already coming under fire from SSH scholars world-wide. Why would we want to replicate this type of problem here in Canada?

5. To solve the existing problems with ethics practices in Canada, SSWHC would like to see more support (e.g., funding; personnel; etc.) within the existing system to alter the makeup of REBs, to provide appropriate educational resources, etc., so that the existing system will better reflect the diversity of research approaches active in Canada. Building a larger bureaucracy, particularly one that will work within a biomedically-inspired accreditation model, is not the solution. Indeed, we see the proposed administrative structure as having such potential to further entrench the harmful practices that currently govern SSH scholars, that we would consider the report more appropriately named *Moving Back*. We need to redirect our collective energies and resources (including financial resources) to local contexts. We need to support REBs in their work, fund additional educational initiatives, and implement recommendations from the existing working committees (like SSHWC) who have been investigating these issues and recommending solutions.
6. We find the amount of money proposed here to implement this new bureaucratic structure to be particularly troubling. Where will the money come from to support this initiative? What will the impact be on SSHRC funding? Will SSH grant dollars be cut to support this system, at a time when SSH scholars (i.e., who are the majority of scholars in Canada, at approximately 70%) are already funded at very low rates relative to the funding provided to scholars in the medical and natural sciences? On page 62 the authors note that “It is possible, for example, that the accreditation function could become self-funding”. We would like to know how that would happen. If not through cuts to existing grant funding, would this be through corporate sponsorship – e.g., pharmaceutical companies? This would have dramatic ethical implications. In fact, there are many potentially problematic, yet unanswered, questions that arise from this report.
7. On that same page, the report notes that “Towards the end of the three-year period, an assessment of the Council’s progress should be conducted. Participants of this assessment, in addition to the Council, should be the federal/provincial/territorial governments and non-governmental stakeholders.”

- (Lines 1475-1476). We are concerned that the assessment participants named here reflect an elite group of insiders and do not include any researchers. At a minimum, those engaged in research activities (and reflecting the diversity of research approaches) must be included in any assessment process. Other individuals/groups with a direct stake in research ethics governance (such as research participants, REB members, university representatives, etc.) might also be included in this type of assessment.
8. The way that individuals would be identified and selected to serve as members (see p. 46-47) is also highly problematic. Any governing body would need to reflect diversity at all levels; this would include national/regional representation as well as disciplinary and methodological. However, there is no discussion here regarding representation from the Fine Arts, let alone the SSH, or from research participants themselves. This is one, concrete, example of the shortcomings of the model presented here; and, it also displays an ignorance of the diversity of research approaches and individuals' perspectives, which are so vital to ensuring that a governance structure will address the needs of all individuals engaged in the research enterprise. Indeed, the voices of research participants (another area where SSHWC has been very active, esp. through our own research activities) are notably absent throughout this report. We need additional research in this area to see whether the existing ethics structure is inappropriate for their needs or if it is adequately addressing their needs.
  9. Again, this report reflects a fundamental fallacy, without presenting evidence that this system will "fix" what needs to be fixed. SSHWC, as a committee, knows what we need to do, at least as far as the SSH community is concerned. We encourage the Sponsors' Table to support us in our work by encouraging PRE to give serious consideration to SSHWC's work so that the TCPS can better serve the SSH community, so that we may see our recommendations implemented in 2008. The experts' report makes no advances in that regard. We do need to "move ahead" as quickly as possible; but this is not the direction to take.

Sincerely,

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