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# SSHWC Recommendations Regarding Privacy and Confidentiality

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## 1. Executive Summary

SSHWC was constituted in 2003 and began by conducting a national consultation with the social science, humanities and creative practice research communities. Privacy and confidentiality issues were identified as a priority area requiring attention. Succeeding years saw SSHWC engage an iterative process of drafting and revising recommendations in an ongoing dialogue with PRE and Canada's research community through further national consultations, preparation of reports and briefing notes, and public presentations of results and draft recommendations in conferences and via web postings.

SSHWC concluded that problems with the existing TCPS arose from two primary sources: (1) wording and coverage within the document; and (2) the way the policy statement was being implemented by REBs. The recommendations with respect to the privacy and confidentiality area outlined in the current document deal primarily with the first source: prospective wording changes to the TCPS. While there are implications to these prospective changes for the review and implementation process, the focus here is on wording/substantive changes. SSHWC's recommendations with respect to ethics review and implementation are more directly addressed in its proposed chapters on *Qualitative Research and Creative Practice*.

That said, SSHWC offers the following recommendations for PRE's consideration with respect to privacy and confidentiality issues for TCPS 2.0:

- 1) **The Right to Confidentiality vs the Right to Recognition.** Notwithstanding the general recognition of the importance of maintaining research confidentiality that has existed within the social sciences – which we reaffirm – when the full diversity of research conducted in the social sciences, humanities and creative arts is considered, the need to maintain confidentiality in any given research project may be anywhere from inappropriate to crucial. Indeed, in some research traditions and research contexts, the principle or right of “recognition for one's contributions” is considered paramount. SSHWC recommends that, in order to better reflect the diversity of the research enterprise, TCPS 2.0 should distinguish between the “right to maintain privacy through anonymity or confidentiality” and the contrasting “right to be identified and recognized for one's contribution.” The challenge to researchers and REBs is to ascertain which right prevails in any given research context and follow through appropriately. [These recommendations are discussed in section 4.1.1 below.]
- 2) **Distinguishing “disclosure of” from “access to” information.** While on the one hand properly affirming the duty of maintaining participant privacy and confidentiality, Section 3 of the current TCPS also asserts that the principle is not absolute. However, the discussion is confusing because it conflates two issues that in SSHWC's view should be distinguished: (1) situations in which competing ethical values might justify disclosure of identifiable information gathered in good faith under a pledge of confidentiality; and (2) circumstances under which researchers might be given access to information that is not publicly available and that was gathered for another purpose. [Section 4.1.2 below distinguishes and discusses the two issues and offers wording that would clarify circumstances in which each is relevant and the options available.]
- 3) **Ethics and Law.** The current TCPS acknowledges that “ethics and law may lead to different conclusions,” but offers little beyond that. SSHWC is of two minds regarding how “ethics and law” should be addressed in TCPS 2.0 and offers both approaches for PRE's consideration.

- a) **Focus on Ethics.** One approach to the “ethics and law” issue is to declare that the TCPS is a document about ethics, that ethical researchers will experience competing pulls for their attention from many other competing value systems – political ideologies, legal constraints and challenges, religious beliefs, university policies, professional codes of conduct, and so forth – and that doing research involves constantly being sensitive to these pulls, recognizing when they conflict, and negotiating those conflicts that do exist in an ethical manner. Including a section on “ethics and law,” according to this view, involves privileging law to the exclusion of other principled systems and diverting the discussion from what is supposed to be the central focus of an ethics policy – the ethical treatment of research participants. [These issues are discussed in Section 4.2.1 below.]
- b) **Matters of Conscience and Responsibility.** To the extent that law does appear in the federal policy statement on ethics, SSHWC believes that two issues need to be addressed in respect to issues of privacy and confidentiality: (a) an explicit recognition that while researchers should make every effort to uphold the ethical principles articulated in disciplinary ethics policies and the TCPS, when the consequences of upholding the principles would result in serious personal consequences (e.g., jail, physical harm, loss of livelihood), any decision for final action should be recognized as a matter of personal conscience; and (b) that researchers, REBs and the institutions under whose name they operate all have responsibilities for the protection of research participants and research confidentiality (and thereby for the integrity of the research enterprise) that should be articulated in the new TCPS. [SSHWC’s proposals for wording on these issues are outlined in Section 4.2.3 below.]
- 4) **Transparency, Openness and Accountability.** In keeping with our continued allegiance to these three principles initially articulated by PRE, SSHWC requests PRE post this document on its website for the research community to read and comment upon.

## 2. Building Consensus: SSHWC’s Consultation Process

It was not long after publication of the initial (1998) version of the TCPS that the Presidents of the granting councils recognized “the need for the TCPS to address more effectively the research ethics issues and contexts in social sciences and humanities disciplines.”<sup>1</sup> The Social Science and Humanities Research Ethics Special Working Committee (SSHWC) was constituted and given the mandate “to provide advice and recommendations on social sciences and humanities priorities for the TCPS.”<sup>2</sup>

SSHWC began work on its mandate with a national consultation designed to identify areas in which the TCPS and processes of review it created were causing difficulty and to establish priorities for the development of recommendations. Privacy and confidentiality issues were among the first to receive SSHWC’s attention. As stated in *Giving Voice to the Spectrum* (SSHWC 2004):<sup>3</sup>

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. (pp.29-30).

<sup>1</sup> Social Sciences and Humanities Research Ethics Special Working Committee: Background and terms of reference. Online at <http://pre.ethics.gc.ca/english/workgroups/sshwc/TermsOfReference.cfm>

<sup>2</sup> *Ibid.*

<sup>3</sup> *Giving Voice to the Spectrum* was the report that emerged from that first consultation. It is online at <http://pre.ethics.gc.ca/english/workgroups/sshwc/SSHWCVoiceReportJune2004.pdf>



The issues identified for attention were:

- (1) ensuring that the privacy and confidentiality provisions outlined in the TCPS would 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;
- (2) greater guidance to the research community concerning the prospect of divergences between ethics and law, particularly with respect to the possibilities of:
  - (a) third parties using legal mechanisms such as subpoenas in an attempt to force researchers and/or institutions to violate the ethical obligation to protect the research participant's right to privacy and confidentiality of data; and
  - (b) researchers encountering unanticipated situations in which they feel ethically compelled to violate a commitment to confidentiality made in good faith (e.g., discovering that the participant intends to commit some grievous harm to a third party).

The Interagency Advisory Panel's (PRE's) response<sup>4</sup> to *Giving Voice to the Spectrum* encouraged SSHWC to continue along the path anticipated in its mandate – to develop recommendations that would help ensure that the TCPS appropriately reflects the diversity of research approaches practiced in the social sciences and humanities:

[T]he Panel invites the Committee and the research community to illuminate further both the unique and shared ethical dimensions of research from qualitative, inductive, non-positivist, non-experimental research paradigms. PRE encourages SSHWC to develop appropriate analyses that may lead to restructuring or potential new sections of the TCPS devoted to the ethics of diverse social sciences and humanities research methods, methodologies and practices. Such work may yield a more inclusive and integrated TCPS for more effective use by REBs, the public, and by researchers from the various communities using such methodologies.

Sharing PRE's expressed commitment to "openness, transparency and accountability," SSHWC engaged that dialogue with the research community. In the realm of privacy and confidentiality issues this included:

- Preparing a report for internal discussion and for PRE that summarized the privacy and confidentiality issues that arose during the consultation that gave rise to *Giving Voice to the Spectrum*.<sup>5</sup>
- Presenting a paper at a PRE workshop prior to the 2005 annual NCEHR conference that outlined privacy and confidentiality issues earmarked for attention on the basis of the 2004 consultation and inviting the research community's participation in the process.<sup>6</sup>
- Presenting a paper at the 2005 annual Congress of the Canadian Federation for Humanities and Social Sciences on issues identified for attention on the basis of the 2004 consultation and inviting the research community's participation in the process.<sup>7</sup>

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<sup>4</sup> PRE's comments are online at

<http://pre.ethics.gc.ca/english/workgroups/sshwc/SSHWC RptMay2004.cfm>.

<sup>5</sup> SSHWC (2004). *SSHWC Analysis and Recommendations Regarding Section 3: Privacy and Confidentiality*. Discussion paper prepared for PRE and internal distribution.

<sup>6</sup> SSHWC (2005). *Privacy and Confidentiality Issues from a Social Sciences and Humanities Perspective: A Work in Progress*. Paper presented at the 3<sup>rd</sup> Annual conference of the Interagency Advisory Panel on Research Ethics (PRE): *Engaging Voices: Deliberating, Debating & Evolving the TCPS*. Ottawa, Ontario: 4 March.

<sup>7</sup> SSHWC (2005). *Social Sciences and Humanities Research Ethics: Privacy and Confidentiality*. Paper presented at the Annual Congress of the Canadian Federation for Humanities and Social Sciences (CFHSS). London, Ontario: 1 June.

- Preparing a briefing note for PRE that outlined the situation regarding statute-based protections for research participants and requesting PRE to encourage the Presidents of the granting councils to seek the development of these for research participants beyond those who participate in research by Statistics Canada.<sup>8</sup>
- Preparing a discussion paper that provided the basis for a second national consultation in 2006 that presented options for issues SSHWC had identified as warranting attention and seeking the research community's comments on these.<sup>9</sup>
- Presenting a paper at the 2006 ACFAS meetings that discussed SSHWC's approach to privacy and confidentiality issues as an illustration of how ethical standards can offer clear guidelines and at the same time respect disciplinary diversity.<sup>10</sup>
- Preparing a report for PRE and the research community providing feedback on the results of the 2006 consultation and outlining SSHWC's recommendations on how to proceed.<sup>11</sup>
- Presentation at a PRE workshop prior to the 2007 annual NCEHR conference that summarized SSHWC's work to date regarding privacy and confidentiality issues, outlined proposed recommendations for the TCPS and expressed the Committee's continuing desire for community input and engagement.<sup>12</sup>
- Articulating a draft set of recommendations for internal discussion among members of SSHWC and the new Chair of PRE and Director of SRE at SSHWC's October 2007 meetings in Montréal.<sup>13</sup>

### 3. Scope of the Recommendations

The various consultations and other communications SSHWC has engaged in with the research community have revealed two distinct sets of issues that must be addressed to improve the manner in which social sciences and humanities research is evaluated by REBs mandated under the TCPS.

The first concerns the **content** of the TCPS itself, and SSHWC has identified, on the basis of its reports, discussion papers and consultations, areas in which the information and principles outlined in the TCPS can be clarified, supplemented, deleted without ill effect, or otherwise

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<sup>8</sup> SSHWC (2005). *A Briefing Note to PRE Regarding Statute-Based Protections for Research Participant Privacy and Confidentiality*. Report prepared for the federal Interagency Advisory Panel on Research Ethics.

<sup>9</sup> SSHWC (2005). *Reconsidering Privacy and Confidentiality in the TCPS: A Discussion Paper*. Discussion paper prepared for the federal Interagency Advisory Panel on Research Ethics (PRE) for a national consultation. [Available online at [http://pre.ethics.gc.ca/english/pdf/sshwc\\_consultation\\_eng.pdf](http://pre.ethics.gc.ca/english/pdf/sshwc_consultation_eng.pdf)]

<sup>10</sup> Lévy, J., and Palys, T. (2006). *Le maintien et le développement de la diversité la recherche: enjeux et défis éthiques*. Paper presented at the 75th Annual Congress of l'Association francophone pour le savoir (ACFAS), McGill University, Montréal, Québec, May 15-19.

<sup>11</sup> SSHWC (2006). *Continuing the Dialogue on Privacy and Confidentiality: Feedback and Recommendations Arising from SSHWC's Recent Consultation*. Discussion paper prepared for the Interagency Advisory Panel on Research Ethics (PRE) and for web distribution to Canada's Social Science and Humanities Research Communities.

<sup>12</sup> SSHWC (2007). *Do you want to know a secret? Do you promise not to tell? Community views on Privacy and Confidentiality*. Paper presented at a PRE/NCEHR Pre-conference Workshop; Ottawa, Ontario, 16 February.

<sup>13</sup> SSHWC (2007). *Toward TCPS 2.0: SSHWC Recommendations Regarding Privacy and Confidentiality*. Working paper for internal distribution only.

improved. The second required area of change is in the **implementation** of the principles already outlined in the TCPS.

The recommendations contained herein deal primarily with the first set of issues, i.e., substantive changes that would allow the TCPS to better reflect the diversity of research conducted in the social sciences, humanities and creative arts. SSHWC understands that TCPS2.0 may well be re-organized significantly, but makes suggestions based on current wording because it best illustrates current shortcomings of the TCPS and routes to a prospective resolution. The Working Committee makes these recommendations hoping that greater clarification and supplementary content will aid REBs in their mandated tasks. However, SSHWC is convinced that no improvement will occur unless changes are also made in the way REBs are constituted and their mandates implemented; SSHWC's recommendations in that regard are included in our proposed chapters regarding *Qualitative Methods and Creative Practice*, and summary list of recommendations.

## **4. Recommendations**

### **4.1 Clarifications Regarding Privacy and Confidentiality Issues**

Section 3 of the TCPS (entitled *Privacy and Confidentiality*) opens with an assertion of the right of privacy of research participants and of the importance of protecting research confidentiality to the research enterprise.

#### ***4.1.1 Considering both Confidentiality and Recognition Traditions***

Notwithstanding the general recognition of the importance of maintaining research confidentiality that has existed within the social sciences – which SSHWC reaffirms -- SSHWC also recognizes that, when the full diversity of research conducted in the social sciences, humanities and creative arts is considered, the need to maintain confidentiality in any given research project may be anywhere from inappropriate to crucial. Indeed, in some research traditions and research contexts, the principle or right of “recognition for one’s contributions” is considered paramount.

In projects involving oral history, for example, it is often inappropriate and disrespectful to fail to identify the research participant. In contrast, researchers who wish to gather sensitive information about a participant’s criminal behaviour or sexual history – or any other information that would be highly stigmatizing, embarrassing and/or result in social censure and even incarceration – need to implement exceptional safeguards to ensure that participants’ right to privacy is adequately protected. As a third example, a video created in the documentary tradition might take care to anonymize images that show a whistleblower or someone engaged in an activity that is highly socially stigmatized, and in another case ensure that a person’s name appears on the screen to recognize their contribution; both might even occur in the same documentary.

Accordingly, SSHWC recommends that TCPS 2.0 recognize and distinguish between the “right to be identified and recognized for one’s contribution” and the “right to maintain privacy through anonymity or confidentiality.” The challenge to both researchers and REBs is to ascertain which right prevails in any given research context and follow through appropriately. If failing to identify participants would be unethical because of the disrespect it would involve, and informed participants assert their desire to be named, then researchers should consider doing so according to the normal principles and practices of their discipline. Where confidentiality is preferred and/or where there is no compelling reason to the contrary, confidentiality would be maintained in a manner commensurate with the needs of the research participants and the project. When the information sought is identifiable as to its source, is highly sensitive (so that the effect of any disclosure would be negative and significant to the participant), and the provision of confidentiality is essential to protecting the research participant from the harm of disclosure, researchers should follow disciplinary best practices and engage any common law or statute-based legal protections that are available to maximize protection of participants.

#### **4.1.2 Distinguishing “Disclosure of” From “Access to” Information**

The current TCPS continues its discussion regarding privacy and confidentiality by stating:

*The values underlying the respect and protection of privacy and confidentiality are not absolute, however. Compelling and specifically identified public interests, for example, the protection of health, life and safety, may justify infringement of privacy and confidentiality. Laws compelling mandatory reporting of child abuse, sexually transmitted diseases or intent to murder are grounded on such reasoning; so too are laws and regulations that protect whistle-blowers. Similarly, without access to personal information, it would be difficult, if not impossible, to conduct important societal research in such fields as epidemiology, history, genetics and politics, which has led to major advances in knowledge and to an improved quality of life. The public interest thus may justify allowing researchers access to personal information, both to advance knowledge and to achieve social goals such as designing adequate public health programs. (p.3-1)*

There are two major themes here:

1. The identification of circumstances in which pledges of research confidentiality made in good faith might be violated; and
2. Consideration of circumstances in which information gathered about persons in confidence in one set of circumstances – for example, health records; prison records; school records – might, without seeking explicit informed consent, be used for research purposes that may or may not have been anticipated at the time the records were created.

While the juxtaposition of the two may make some sense in so far as both are examples of situations where privacy is not absolute, SSHWC suggests the two issues of “disclosure of” and “access to” information need to be distinguished more clearly as each has different implications and triggers different sets of issues for researchers and REBs to consider. However, the difficulties in the paragraph are not limited to that. A detailed analysis of the paragraph will help identify sources of difficulty and routes to a prospective resolution.

*The values underlying the respect and protection of privacy and confidentiality are not absolute, however.*

This seems a virtual truism; surely no single value is absolute. Given recognition of that state of affairs, however, the question is how one proceeds nonetheless.

##### **4.1.2 (a). Case-by-Case Consideration of Circumstances Possibly Warranting Disclosure**

One concern SSHWC heard expressed in the consultations is that to the extent one focuses on situations where confidentiality can be transgressed, the general principle of research confidentiality is undermined. SSHWC accepts that concern and accordingly suggests that any mention of permissible disclosures that violate research confidentiality should have their rarity underlined, and the circumstances that might trigger their activation clarified.

*Compelling and specifically identified public interests, for example, the protection of health, life and safety, may justify infringement of privacy and confidentiality.*

SSHWC believes this specification of exceptions is too broadly worded and suggests that instead of identifying general categories that might justify disclosure, case-by-case consideration be suggested and researchers’ ethical obligations underlined.

*Laws compelling mandatory reporting of child abuse, sexually transmitted diseases or intent to murder are grounded on such reasoning; so too are laws and regulations that protect whistle-blowers.*

This section is confusing in part because it misrepresents law. It makes reference to “mandatory reporting of child abuse” as if this is a universal when it is not; in British Columbia, for example, the relevant legislation refers to mandatory reporting for “children in need of protection,” which is quite a different concern. We know of REBs, for example, who have impeded retrospective research with adult women on the grounds that any references to abuse they experienced as children would require reporting, but that misperception (as it is in British Columbia, at least) is exacerbated by the TCPS. The same is true of “intent to murder;” while a situation may arise in which a researcher feels ethically compelled to report such intent, we know of no law that requires them to do so. The sentence also implies a social consensus about the wisdom of mandatory reporting laws that does not exist; while some extol their virtues, others argue they only push the relevant behaviour further underground and make research on what are arguably some of society’s most pressing social issues impossible.

The Working Committee is also unclear about the reference to whistle-blowers. Is the TCPS suggesting that researchers should be whistle-blowers? That would seem to conflict with the admonition in TCPS Section 2.2 that, “Researchers should avoid being put in a position of becoming informants for authorities or leaders of organizations.” Or is it a suggestion that researchers would be protected as whistle-blowers in the event they were to violate a research confidence? If so, we suggest that such a statement is misplaced; the focus in the TCPS should continue to be on the protection of research participants, not on the protection of researchers *from* research participants.

#### **4.1.2 (b). Secondary Access to Private Information for Research Purposes**

*Similarly, without access to personal information, it would be difficult, if not impossible, to conduct important societal research in such fields as epidemiology, history, genetics and politics, which has led to major advances in knowledge and to an improved quality of life. The public interest thus may justify allowing researchers access to personal information, both to advance knowledge and to achieve social goals such as designing adequate public health programs.*

While SSHWC agrees with the general sentiment expressed here regarding the value of research, it is not “similar” to the text that precedes it in terms of the ethical issues involved. Instead, the allusion here is to a separate issue of the circumstances under which researchers might ethically make secondary use of “private” information for research purposes that was gathered for another purpose.

#### **4.1.3 Proposed Changes in Framing/Wording**

Taking those portions of the TCPS discussed above, restating them with changes reflecting the reorganization suggested above, and guided by the principles outlined in *Continuing the Dialogue*, leads us to recommend the following prospective wording:

The values underlying the respect and protection of privacy and confidentiality are not absolute, however. In some instances there will be a competing right to be identified for one’s contributions, and researchers and REBs will need to pay heed to disciplinary standards and the perspective of participants to recognize whether that right, or the right to privacy and confidentiality, prevails in any given research context.

Even when the right to confidentiality prevails, however, compelling and specifically identified public interests, for example, the protection of health, life and safety, may, in very exceptional circumstances, justify infringement of privacy and confidentiality. In such circumstances the researcher *may* (not “must”) violate the confidence only to the degree necessary to prevent the harm and while still maintaining the rights of the participant and the researcher’s responsibilities to him/her, which remain unchanged. If time allows, researchers considering a possible disclosure should consult with trusted

colleagues regarding an appropriate course of action. Universities should ensure that the researcher has access to the REB and appropriate legal help should either prove necessary.

Researchers also should be aware of mandatory reporting laws such as those that exist in some jurisdictions pertaining to the reporting of victims of child abuse and/or children in need of protection and in relation to some sexually transmitted diseases. However, as outlined in section 2.2, researchers who commence research on such topics must ensure they “avoid being put in a position of becoming informants for authorities or leaders of organizations.” For example, asking questions about an issue knowing one would report persons who respond in a particular way should be avoided.

Infringements of personal privacy by researchers who seek access to information gathered in confidence for another purpose (e.g., health, education, school or prison records) may be permissible. Without access to such information, it would be difficult, if not impossible, to conduct important societal research in such fields as epidemiology, history, genetics and politics, which has led to major advances in knowledge and to an improved quality of life. The public interest may justify allowing researchers access to personal information, both to advance knowledge and to achieve social goals such as designing adequate public health programs, particularly when the data can be compiled without identifiers. Ethics review is an important process for addressing the conflict of societal values that is involved in this situation. REBs should ensure that the researcher shows evidence of having considered the balance between the need for research against infringements of privacy, and has minimized any necessary invasions of privacy. Individuals should be protected from harm caused by unauthorized use of identifiable information in which they believed they had an expectation of privacy and the benefit of confidentiality.

## **4.2 Ethics and Law**

SSHWC’s consultations and previous reports on privacy and confidentiality issues have identified several issues for attention regarding the intersection of ethics and law. Most recently SSHWC’s “*Continuing the Dialogue*” report – which offered feedback to PRE and the research community regarding the Winter 2006 privacy and confidentiality consultation and outlined in general terms the recommendations SSHWC would pursue – identified three areas of wording change for the TCPS, including: (a) clarifying the options open to researchers in those rare instances when ethics and law “lead to different conclusions;” (b) clarifying and affirming the roles and responsibilities of researchers, REBs and universities/institutions when third parties challenge research confidences; and (c) including reference to statutory and common law mechanisms that can be incorporated into the research design process to maximize legal protections for research participants and researchers.

### ***4.2.1 When Ethics and Law “Lead to Different Conclusions”***

*Continuing the Dialogue* included the following recommendation:

The TCPS already recognizes that “ethics and law may lead to different conclusions” and the funding agencies have acknowledged the right of researchers to make a personal choice of conscience about what to do when and if, in the last instant, that divergence were ever to occur. While SSHWC does not advocate defying legal orders, neither does it preclude the right of researchers to do that for ethical reasons when all other avenues have been exhausted. SSHWC suggests that wording be developed for the TCPS along the lines of ... Canadian Psychological Association Code of Ethics (2000) ... Principles IV.17 and IV.18...

The difficulties alluded to above are rooted in the TCPS section entitled “Context of an Ethics Framework,” in section F – “Ethics and Law” – where law is given a special status in the TCPS

beyond any other sets of standards or values that may interact with ethical principles. Like the duty to obey ethical principles such as confidentiality, the duty to obey law is not absolute; nor is it the only set of standards or values that will interact with the ethical principles set out in the TCPS.

All admonitions in the early portion of the TCPS that focus on objectives and principles remind readers that the intent of the Policy Statement is to encourage researchers' adoption of and adherence to the highest ethical standards. SSHWC believes that "being ethical" should remain the core intent and focus of the policy, while understanding that various other elements of life – politics, university policy, family responsibilities, the law – interact with our ethical obligations in a variety of ways from obstructive to supportive. To focus on law to the exclusion of other sets of standards and values commences a discussion that is not unreasonable to engage, but is only a partial discussion that pulls the discussion away from what is ethical. With this in mind, we proceed with a detailed analysis of the TCPS section on Ethics and Law.

*The law affects and regulates the standards and conduct of research involving human subjects in a variety of ways, such as privacy, confidentiality, intellectual property, competence, and in many other areas. Human rights legislation prohibits discrimination on a variety of grounds. In addition, most documents on research ethics prohibit discrimination and recognize equal treatment as fundamental. REBs should also respect the spirit of the Canadian Charter of Rights and Freedoms, particularly the sections dealing with life, liberty and the security of the person as well as those involving equality and discrimination.*

SSHWC is not clear what this paragraph adds to the TCPS. It seems a collection of truisms and motherhood statements that have little to do with the everyday practice of REBs and researchers. We have never heard of an allegation anywhere in the country, for example, that any researcher or institution has proposed to violate the *Canadian Charter of Rights and Freedoms*. Everything in the paragraph beyond the preambular first statement could be deleted – and the opening statement itself could be improved --with no loss to the Policy Statement.

*This legal context for research involving human subjects is constantly evolving, and varies from jurisdiction to jurisdiction. For this reason, researchers, institutions and REBs should have recourse to expertise to identify legal issues in the ethics review process.*

SSHWC agrees that there may be times when legal advice would be useful, and also that it is useful to researchers and REBs to include this sentence as a reference that can be cited when such advice is sought.

*However, legal and ethical approaches to issues may lead to different conclusions. The law tends to compel obedience to behavioural norms. Ethics aim to promote high standards of behaviour through an awareness of values, which may develop with practice and which may have to accommodate choice and liability to err. Furthermore, though ethical approaches cannot preempt the application of the law, they may well affect its future development or deal with situations beyond the scope of the law.*

SSHWC sees this as an important statement as far as it goes – acknowledging that ethics and law can lead to different conclusions – and recognizing it as a matter of conscience what choice the researcher will make in those rare instances where the two conflict. However, the Working Committee believes that the statement could be more explicit in its articulation of alternatives, and needs to be so to make clear the resolution the Presidents of the granting agencies affirmed when these issues were actively being discussed several years ago.<sup>14</sup>

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<sup>14</sup> See letter on behalf of the three granting councils from Anne-Marie Monteith, NSERC Research Ethics Officer, dated 27 April 2000, regarding ethics and law. The letter may be seen online at <http://www.sfu.ca/~palys/TCPSFAQ.pdf>

#### ***4.2.2 Roles and Responsibilities When Confidentiality is Challenged***

In *Continuing the Dialogue* SSHWC undertook to supply wording that would clarify the roles and responsibilities of researchers, research ethics boards and institutions when research confidentiality is challenged by a third party. Although such situations are extremely rare, particularly in Canada — and it is worth noting that no Canadian researcher that we have ever heard of has ever been ordered by a court to divulge confidential, identifiable research information — acceding to such challenges could bring devastating harm to research participants and, in turn, seriously undermine the integrity and perceived integrity of the research enterprise. It also would undermine academic freedom to do research on the controversial social issues and vulnerable populations who often are the object of such legal processes. Accordingly, SSHWC believes that such challenges should be resisted vigorously.<sup>15</sup>

At present these issues are addressed in the preamble to Section 3 of the TCPS. We begin with a detailed analysis of the section:

*The situation may arise where a third party attempts to gain access to research records, and hence to breach the promise of confidentiality given by the researcher as part of a research project approved by the REB. By that time, the matter has passed from the hands of the REB.*

Although the matter may have passed from the hands of the REB in the sense that the situation will not have arisen unless the researcher received an approval and then went ahead with his/her research, it would be erroneous to believe that the REB has no subsequent role in the defense of research confidentiality.

*The researcher is honour-bound to protect the confidentiality that was undertaken in the process of free and informed consent, to the extent possible within the law. The institution should normally support the researcher in this regard, in part because it needs to protect the integrity of its own REB.*

SSHWC agrees with this sentiment as a minimum standard, but notes it is purely reactive in scope. The literature suggests that universities and researchers can better help themselves and their research participants by proactively anticipating ways to protect their participants from the possibility of legal challenge and having policies in place that allow a timely and effective legal response when and if a challenge arises.<sup>16</sup>

*If the third party attempts to secure the research data by subpoena, it is legitimate for the researcher and the institution to argue the issue in court. The records of the REB and of the consent might be useful as part of this counter-argument, or may be requested by those seeking access. However, if the court issues a subpoena, legal appeals will probably be the only legal option open to the researcher to protect the confidentiality of the records.*

SSHWC supports this view but would prefer more specific information of the sorts of records the researcher and the REB should create and ensure are on hand to best defend against any challenges to research confidentiality. At the moment this likely would involve anticipating a case-by-case assertion of research participant privilege by invoking the Wigmore criteria. These

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<sup>15</sup> SSHWC has previously recommended that PRE/SRE advise the Presidents of the granting councils to encourage Parliament to develop statute-based protections for research participants. Another way a research participant privilege can be recognized is through the common law. Vigorous resistance to any threat to research confidentiality not only demonstrates to research participants that we care for their welfare and will protect their rights, but also shows to the courts the importance the research community attaches to the principle.

<sup>16</sup> See, for example, Traynor, M. (1996). Countering the excessive subpoena for scholarly research. *Law and Contemporary Problems*, 59(3), 119-148.



criteria, named after John Henry Wigmore,<sup>17</sup> former Dean of Law at the Northwestern University Law School who identified them on the basis of his search for common law traditions in Canada, the United States and England,<sup>18</sup> require that: “(1) the communications must originate in a *confidence* that they will not be disclosed; (2) this element of *confidentiality must be essential* to the full and satisfactory maintenance of the relation between the parties; (3) the *relation* must be one which in the opinion of the community ought to be sedulously *fostered*; and (4) the *injury* that would inure to the relation by the disclosure of the communications must be *greater than the benefit* thereby gained for the correct disposal of litigation.”<sup>19</sup>

*In the process of free and informed consent, researchers should indicate to research subjects the extent of the confidentiality that can be promised, and hence should be aware of the relevant law.*

Clearly researchers should be honest with research participants about what they and their institutions will do when faced with a challenge to research confidentiality. However, the reference to law here is confusing to the extent that it might be taken to imply that the policy statement’s allegiance is to law rather than ethics in the event that the two “lead to different conclusions.” Indeed, the reference to law seems gratuitous as there are many other factors that also might influence the extent to which confidentiality “can” be promised, e.g., in focus groups researchers can do their part to preserve confidentiality, but whether confidentiality is actually kept depends in part on factors beyond the researcher’s direct control (i.e., other participants).

#### **4.2.3 Proposed Wording Regarding Ethics, Law and the Protection of Research Confidentiality**

SSHWC recommends that the wording of the Ethics and Law section of the TCPS be changed to the following:

The law affects and regulates the standards and conduct of research involving human subjects in a variety of ways, such as privacy, confidentiality, intellectual property, competence, and in many other areas. Researchers are expected to familiarize themselves with the laws and regulations of the societies in which they work that are related to their activities as researchers. However, legal and ethical approaches to issues may lead to different conclusions. The law tends to compel obedience to behavioural norms; ethics aim to promote high standards of behaviour through an awareness of values. If the laws or regulations that are applied to one’s research seriously conflict with the ethical principles contained in this policy statement, researchers will do whatever they can to uphold the ethical principles. Ethical approaches cannot preempt the application of the law, but they may well affect its future development or deal with situations beyond the scope of the law. Nonetheless, if upholding the ethical principles could result in serious personal consequences (e.g., jail or physical harm), decision for final action would be considered a matter of personal conscience. Researchers should consult with colleagues if faced with an apparent conflict between abiding by a law or regulation and following an ethical principle, unless in an emergency, and seek consensus as to the most ethical

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<sup>17</sup> M. Jackson, QC, & M. MacCrimmon (1999). *Research Confidentiality and Academic Privilege: A Legal Opinion*. Commissioned by Simon Fraser University (SFU) Research Ethics Policy Revision Task Force, online: <http://www.sfu.ca/~palys/JackMacOpinion.pdf> (date accessed: 19 January 2008).

<sup>18</sup> J. H. Wigmore (1961). *Evidence in Trials at Common Law*, vol. 8 (McNaughton rev.) Boston: Little, Brown. (original edition in 1905).

<sup>19</sup> For a peer-reviewed article that outlines general strategies of how researchers can anticipate these criteria in their research see T. Palys & J. Lowman (2000). Ethical and Legal Strategies for Protecting Confidential Research Information. *Canadian Journal of Law and Society*, 15(1), 39-80. For more specific project-related advice, legal counsel might be sought.

course of action and the most responsible, knowledgeable, effective, and respectful way to carry it out.<sup>20</sup>

SSHWC recommends the following wording for the TCPS's elaboration of responsibilities for the protection of research confidentiality:

### **Protecting Research Confidentiality**

When researchers gather sensitive identifiable information from research participants under an ethical pledge of confidentiality, the protection of that confidentiality is integral to the protection of both research participants and the integrity of the research enterprise. Although third-party challenges to research confidentiality are extremely rare in Canada, which makes pledges of "strict confidentiality" a reasonable promise requiring no further qualification, easily-incorporated proactive protection and vigorous reactive effort will help ensure this element of research integrity will remain intact. Researchers, REBs and research institutes and institutions all have a role to play.

Researchers should:

- (a) follow disciplinary standards and practices for the collection and protection of confidential information;
- (b) behave in a manner commensurate with the level of sensitivity of any identifiable information they hold (for example, in the case of very sensitive data, by anonymizing the data at the earliest convenience; by holding the raw data in a locked cabinet or secret location away from their office); and
- (c) incorporate any statute-based or common law legal protections (e.g., the Wigmore criteria) that are available to them when designing their research.

Research Ethics Boards should:

- (a) ensure in cases where confidentiality is essential and any disclosure would harm participants that there is an archival record (e.g., in the proposal they review) that confidentiality is considered essential for gathering valid information;
- (b) ensure that no gratuitous archival record is created (for example, consent statements signed by and/or that identify the participant) that would undermine the case;
- (c) be prepared to challenge any requests made to the REB for identifiable information when that information was gathered under a pledge of confidentiality.

University administrations and research institutes should:

- (a) create policies that give researchers and REBs easy access to qualified legal help that is independent of the university's own lawyers.

Notwithstanding these preparations, the situation may arise where a third party attempts to gain access to research records, and hence to breach the promise of confidentiality given by the researcher as part of a research project approved by the REB. If this occurs, the researcher is honour-bound to protect the confidentiality that was undertaken in the process of free and informed consent, at least to the extent possible within the law. The institution should normally support the researcher in this regard, in part because it needs to protect the integrity of its own REB. If the third party attempts to secure the research data by subpoena, it is legitimate for the researcher and the institution to argue the issue in court. The records of the REB and of the consent might be useful as part of this counter-argument, or may be requested by those seeking access. However, if the court

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<sup>20</sup> The added material in this proposed change is taken or adapted from Principles IV.17 and IV.18 of the Canadian Psychological Association Code of Ethics (2000).

issues a subpoena, legal appeals will probably be the only legal option open to the researcher to protect research participant confidentiality.

## **5. Transparency, Openness and Accountability**

In the course of establishing its priorities and developing its recommendations in the area of privacy and confidentiality, as is true of its other initiatives, SSHWC has followed a process that is “transparent, open and accountable.” Consistent with those principles, SSHWC recommends that this document be made public on the PRE/SSHWC web site as the culmination of its efforts in the area of privacy and confidentiality.