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# **Continuing the Dialogue on Privacy and Confidentiality:**

Feedback and Recommendations Arising from  
SSHWC's Recent Consultation

**30 November 2006**

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# Table of Contents

<b>1. SSHWC’S PRIVACY AND CONFIDENTIALITY CONSULTATION.....</b>	<b>3</b>
<b>2. APPROACHES TO CONFIDENTIALITY .....</b>	<b>3</b>
<b>3. A “SUBJECT-CENTERED PERSPECTIVE” ON PRIVACY AND CONFIDENTIALITY .....</b>	<b>4</b>
3.1 SOME INTERIM PRINCIPLES.....	5
<b>4. ETHICS AND LAW.....</b>	<b>5</b>
4.1 EXISTING AND POSSIBLE CONVERGENCES OF ETHICS AND LAW.....	6
4.1.1 <i>Possible Protections in Common Law through the Wigmore Criteria.....</i>	6
4.1.2 <i>Statute-Based Protections .....</i>	7
4.1.3 <i>Unknown Levels of Protection from “Protection of Privacy” Legislation .....</i>	8
4.2 POSSIBLE SOURCES OF CONFLICT BETWEEN ETHICS AND LAW .....	8
4.2.1. <i>Criminal Prosecutions and High Stakes Litigation: Protecting Confidentiality is a Shared Responsibility.....</i>	8
4.2.2 <i>The Researcher’s Dilemma.....</i>	10
4.2.3 <i>Avoiding the Research Equivalent of Caveat Emptor .....</i>	11
4.2.4 <i>Unanticipated Heinous Discovery .....</i>	12
4.2.5 <i>Mandatory Reporting Laws .....</i>	13
<b>5. MISSING ISSUES.....</b>	<b>15</b>
5.1 COLLECTIVITIES .....	15
5.2 PRIVACY LEGISLATION AND SECONDARY DATA BASES .....	15
<b>6. COMMUNICATING WITH THE RESEARCH COMMUNITY .....</b>	<b>17</b>
<b>7. APPENDIX: LIST OF RECOMMENDATIONS .....</b>	<b>18</b>

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# Continuing the Dialogue on Privacy and Confidentiality: Feedback to PRE and the Research Community Regarding SSHWC's Recent Consultation

SSHWC  
28 November 2006

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## 1. SSHWC's Privacy and Confidentiality Consultation

The SSHWC discussion paper, *Reconsidering Privacy and Confidentiality in the TCPS*, (hereafter, "*Reconsidering*") was disseminated widely and posted at the PRE web site initially from 7 February to 10 April 2006; the period was extended until 10 May 2006 and no late submission was ignored. In the end, 36 submissions were received from researchers, research ethics boards, research administrators, and disciplinary and professional associations, with a broad regional representation. Known disciplinary affiliations of those who made submissions included medicine, sociology, political science, epidemiology, mathematics, philosophy, and psychology. The majority of REBs were multidisciplinary or social science and humanities-oriented. One health REB responded, and one REB submission was anonymous.

SSHWC thanks the diverse cross-section of the research community who took part for their diligence and the high quality of their submissions. In cases where it appeared a consensus was achieved, this discussion paper outlines suggested next steps. Where constructive criticism was offered that revealed problems with our preliminary formulations, we have modified or withdrawn proposals. Two issues of import that had not yet been addressed are drawn to PRE's attention.

## 2. Approaches to Confidentiality

The *Reconsidering* discussion paper suggested that it might be useful to distinguish between situations where confidentiality is: (a) unnecessary; (b) freely waived by the participant; (c) out of the researcher's control; (d) undesirable or disrespectful; or (e) essential. The paper further affirmed that, as a matter of general principle, the decision to disclose identifiable personal information rests with the participant.

Overall, the submissions supported these distinctions and the general principle of recognizing the need for situational sensitivity. Particular appreciation was expressed for the discussion paper having broached the issue of situations where confidentiality is "out of the researcher's control." The example used in *Reconsidering* was that of focus group interviews, where maintaining confidentiality relies not only on the researcher, but also on all those who are part of the focus group. Submissions also affirmed the need to recognize situations where the provision of confidentiality might well be disrespectful and a violation of local norms. An example here would

be some interviews with Indigenous Elders, where it is often important to identify the Elder out of respect.

However, several submissions pointed to weaknesses in the typology. Particular concern was expressed regarding the first and second alternatives in the list – where confidentiality is “unnecessary,” and where it is “freely waived” by the participant. The main worry was that such notions may trivialize the commitment to confidentiality and thereby erode it. Even in situations where the information discussed may not be particularly private and is of the order that one might discuss with strangers at a party – an example used in the *Reconsidering* discussion paper – submissions argued the expectation of confidentiality still should prevail. One submission from a disciplinary association reminded us that the research interview is a context whose unique dynamics should be appreciated:

There is a potential danger in investigators having an option for a participant to waive confidentiality. That is, the contextual factors involved in research undoubtedly influence the information that is disclosed - they are not parallel situations (e.g., talking about one's attitudes about personal matters at a party is not the same as discussing these things as part of a research study). The context inevitably influences the parameters of the disclosure. Having this as an option also invites discretion by the researcher about what constitutes such 'public information'. Again, in the absence of clear guidelines, this seems potentially risky in terms of instituting waiver of confidentiality in circumstances where such a protection would indeed be warranted. It may also be unnecessary. The potential benefit of such a provision is also not clearly outlined or substantiated in the document.

Concern also was expressed about situations where prospective participants might not fully appreciate the implications of waiving confidentiality, or may not be fully capable to make such a choice.

SSHWC concludes from the consultation that the research community affirms the general principle of research confidentiality as a default expectation, but sees two exceptional situations that should be recognized in the TCPS – when confidentiality is out of the researcher’s control, and where the provision of confidentiality would be disrespectful.

**Recommendation for SSHWC Action:**

SSHWC proposes to develop wording for inclusion in the TCPS that reaffirms the general principle of confidentiality while noting two exceptions – when confidentiality is out of researcher’s control (where confidentiality should be encouraged but the capacity of the researcher to safeguard it is limited); and where the provision of confidentiality would be disrespectful.

### **3. A “Subject-Centered Perspective” on Privacy and Confidentiality**

Submissions expressed support for promoting research regarding participants’ perspectives on confidentiality issues, and several commented on the pilot project that some members of SSHWC have undertaken in an effort to promote the generation of knowledge about these perspectives.

Suggestions went in opposite directions, however, on the wisdom of SSHWC being involved in such research itself. One disciplinary association suggested that SSHWC should go so far as to

institutionalize the process, stating, “a more regular and systematic survey of research participants should be added both to the current consultation process and to assist in the future evolution of the TCPS.” Another submission from an individual, while supporting the desirability of such research, wondered aloud about the wisdom of SSHWC (or any other part of the PRE “family”) undertaking it:

[T]he authors talk about SSHWC developing a participants’ perspective on privacy and confidentiality. This raises a question about the locus of research on research ethics. The Interagency Panel does need to be informed by good research on our system of research ethics oversight. But is it in the best position to conduct such research itself? Might this not better occur through research awarded through peer reviewed processes by the Research Councils (perhaps acting in a coordinated way)?

SSHWC’s involvement in this area was purely exploratory and designed to encourage and promote the involvement of other researchers in this area. SSHWC agrees with the second author who suggests that any future research is better undertaken by others.

**Recommendation to PRE:**

SSHWC recommends PRE convey to SSHRC and the other granting agencies SSHWC’s view, reaffirmed in the submissions, of the value of research that attempts to better understand research ethics issues from participants’ perspectives. The Working Committee also hopes that SSHRC and the other granting agencies might consider allocating dedicated funding to encourage members of the research community to do research that contributes to those understandings.

### **3.1 Some Interim Principles**

In lieu of an existing literature on research participant perspectives and how these might be accommodated in the proposal and review process, SSHWC suggested some interim principles for the research community’s consideration. The essence of the principles was the more socially distant the senior researcher(s) and REB were from the target population for the research, the greater the obligation for the researcher and REB to take steps to ensure that participant perspectives are solicited and accommodated.

While generally supportive of the importance of taking the “subject-centered perspective” advocated by the TCPS (e.g., see p. i-7), reactions of the research community toward the interim principles outlined in the *Reconsidering* document expressed caution about their prospective implementation. Several submissions problematized the concept of “social distance” on which the interim principles relied, and several others saw the principles as crossing the boundary into micro-managing. In the end, SSHWC agreed with these criticisms and will pursue them no further.

## **4. Ethics and Law**

The Ethics and Law section occupied a significant portion of the document, and many submissions included comments about the intersection of ethics and law and SSHWC’s recommendations in regard thereto.

## 4.1 Existing and Possible Convergences of Ethics and Law

This section of the discussion paper began by outlining areas where the ethical principles of confidentiality and protection of the research participant and law can coincide because legal protections exist in statute or can be triggered through the common law.

### ***4.1.1 Possible Protections in Common Law through the Wigmore Criteria***

When third parties challenge research confidentiality and attempt to secure identifiable information to pursue their own non-research interests, historical practice and the expectation affirmed in the TCPS is that researchers will resist. While it is possible that a constitutional defence might be asserted by invoking the participant's right to privacy or the researcher's rights of freedom of expression, defending research confidentiality "to the extent possible within the law" (as the TCPS expects) most likely would be done by invoking the Wigmore criteria, which the Supreme Court has identified as the proper means for asserting privilege on a case-by-case basis. The discussion paper outlined ways researchers could maximize the likelihood of a researcher-participant privilege being recognized by anticipating those criteria in their research design in situations where information is sensitive, the source of the information is identifiable, and disclosures would be harmful to a participant.

The submissions welcomed this information and agreed that anticipating these requirements at the design and review stages – by incorporating design criteria that fulfilled court requirements – would be one part of an effective strategy of safeguarding research confidentiality and making every effort to ensure that ethics and law coincide. The major question was not whether to convey this information, but where, and in what detail. One submission from a professional association summarized the alternatives well:

[We] endorse the call to include guidance on the Wigmore Criteria in the TCPS. The research community must be actively prepared to defend privacy and confidentiality. The structuring of projects in anticipation of third party intervention is one important means to achieve this end. While [we] support the substantive recommendation, it does query the amount of additional detail that a revised version of the TCPS can successfully carry. [We are] not opposed in principle to expanding areas of the document, but ... suggest that careful thought should first be given to how much ground should be covered in TCPS and how much outside it. Length and detail have advantages, but also may entail inflexibility. With specific reference to Wigmore, it may be appropriate to articulate the broad foundations of the duties in fairly general terms in the TCPS and develop more complete guidelines in a separate advisory document or an appendix to TCPS.

SSHWC agrees with those sentiments.

#### **Recommendation for SSHWC Action:**

SSHWC proposes to write wording for the TCPS that mentions the Wigmore criteria and describes in general terms researcher and REB responsibilities to properly anticipate the criteria when participants could be harmed by disclosures that would be of interest to third parties.

### **4.1.2 Statute-Based Protections**

When statute-based protections that might exist for Canadian researchers were outlined, the discussion paper noted briefly the statute-based protections called “confidentiality certificates” and “privacy certificates” that might be available to them for research done in the United States on health and criminological issues, respectively. Also mentioned was the statute-based privilege that exists in Canada for Statistics Canada researchers and those academics who receive status as “deemed researchers.”

Concern about and interest in confidentiality certificates for research done in Canada was expressed by more than a third of the submissions. A cross section of the research community from across the country including individual researchers, REBs, professional and disciplinary associations, French and English, health researchers and across the social sciences spontaneously mentioned their belief in the need for such protection and how it would help resolve the possibility of divergences of ethics and law. A few examples from the submissions follow:

The division between an “ethics first” and a “law first” perspective is problematic. Researchers and REBs should not be faced with this choice. ... It would be more appropriate for the Tri-Council to request legislation affording privileged communication between researchers and their respondents. Perhaps an exploration of the applicability of the common law approach to privilege would be beneficial. Forcing the researcher into making the Procrustean choice of either a legal or ethical approach, is itself ethically unacceptable. Statistics Canada affords privileged communication to its employees and to their academic consultants, so a Canadian precedent for this legislative remedy already exists. ... If as a society, we deem it important to study illegal behaviours to learn about the drug trade, prostitution, and other criminal behaviours, then we need to provide the protection to researchers and respondents to encourage these lines of inquiry. (Submission from an REB Chair)

Canada should follow the American lead with regard to confidentiality or privacy certificates. Since this protection falls under provincial jurisdiction, we could hold talks to extend it to all of Canada. (Submission from a provincial Ministry that supports research on health issues)

We firmly believe that Confidentiality Certificates, used in the U.S., should be used in Canada. This will ensure that the confidentiality of participants is protected, no matter the research topic. (Submission from a University REB)

When reading through the document, I was anticipating that the authors would call for the creation in Canada of a statute-based protection equivalent to the certificate of confidentiality available in the United States. Yet, the document was silent in this matter. Perhaps the authors felt it was beyond the remit of this document, which was focused on revisions to the TCPS. Nonetheless, I think it would be valuable to exhort the CIHR to lobby for similar statutory protections. Perhaps the authors felt that the Wigmore Criteria sufficed. I was not so persuaded. (Submission from an individual researcher)

#### **Recommendation to PRE:**

The consultation revealed diverse support across the research community for the development of statute-based protections for research participant confidentiality along the lines of US-based “confidentiality certificates” and “privacy certificates.” SSHWC asks that PRE convey these affirmations to the Presidents of the granting agencies along with its recommendation that the Presidents more actively explore this legislative alternative for further discussion with their respective Ministers.

### **4.1.3 Unknown Levels of Protection from “Protection of Privacy” Legislation**

The *Reconsidering* discussion paper noted that much more needs to be known about the levels of protection associated with privacy legislation, and many of the submissions expressed the wish that the SSHWC discussion paper would have included discussions of the federal *Personal Information Protection and Electronic Documents Act* (PIPEDA) and provincial freedom of information and protection of privacy (FOIPOP) legislation. We agree that such analyses would be beneficial, but also recognize that doing so is beyond SSHWC’s mandate and capacity.

#### **Recommendation to PRE:**

An analysis of the implications of federal PIPEDA and provincial FOIPOP legislation on the research enterprise is beyond the capacity of SSHWC to undertake. Such analyses would, however, be very useful as a prerequisite to making recommendations as to how research possibilities and privacy rights might be balanced and mutually accommodated. Accordingly, SSHWC recommends that PRE encourage CIHR and SSHRC to promote such analyses through existing or prospective grant programmes.

## **4.2 Possible Sources of Conflict Between Ethics and Law**

The discussion document focussed on three areas of potential conflict between the law and the ethical duty of confidentiality to research participants: (a) Criminal Prosecutions and Civil Litigation; (b) Unanticipated “Heinous Discovery”; and (c) Mandatory Reporting Laws.

### **4.2.1. Criminal Prosecutions and High Stakes Litigation: Protecting Confidentiality is a Shared Responsibility**

This section of the discussion paper addressed the efforts of third parties to use legal force – typically via subpoena – to secure, for their own purposes, identifiable research information that was gathered in confidence. Submissions that commented on this section reaffirmed the need for the defence of confidentiality to be vigorous, and for the protection of research confidentiality to be recognized as a shared responsibility involving researchers, REBs, university administrations, the granting agencies and professional and disciplinary associations.

Generally speaking, submissions expressed the view that researchers and REBs were being conscientious about protecting research confidences, but that university administrations might be reminded more explicitly of their responsibilities: if universities want to reap the benefits that are associated with being research institutions they should recognize that defending research participants is part of the cost of doing business. It was most noteworthy that these same protective sentiments were expressed across many different groupings – individual researchers, REBs, professional and disciplinary associations, and across the social and health sciences. The remarks of one professional association are illustrative:

[The SSHWC document identifies] the ethical obligation to protect research confidentiality from third party challenges as a shared responsibility of researchers, REBs and the institutions that employ and fund them. In particular, they state that university administrations should be prepared to defend threats to confidentiality not only because of the moral obligation they have to protect research participants, but also as a defence of academic freedom and the research enterprise.



[Our association] unequivocally endorses this call. University and college administrations are capable of extraordinary courage in the face of attacks on academic freedom. Bitter experience also demonstrates that they can pusillanimously surrender to, or actively collaborate with, third party attacks on academic freedom.

Or, as an REB stated more directly,

We also believe that either the TCPS or MOU should require that institutions protect their researchers in situations where they become identified as “persons of interest” or are the subject of legal action regarding confidentiality.

### **Recommendations for SSHWC Action:**

SSHWC should propose wording for the TCPS that affirms the need for vigilance in the protection of confidentiality, and offers guidelines for researchers, REBs and university administrations. These would include:

**A. Researchers:** (a) should incorporate suggested strategies for the protection of confidential information;<sup>1</sup> (b) should anticipate the Wigmore criteria when confidentiality is essential<sup>2</sup> and there would be negative repercussions to the participant if disclosures were to occur;<sup>3</sup> and (c) if they are designated a “person of interest” or there is an actual legal advance made to them (e.g., via subpoena), they should inform the REB and seek legal help.

**B. Research Ethics Boards:** (a) should ensure that in cases where confidentiality is essential and a disclosure could harm participants, there is an archival record (e.g., in the proposal) of the fact confidentiality is considered essential for the acquisition of valid data, as well as the REB’s recognition and acceptance of that fact; (b) should be prepared to challenge any third party requests for confidential research information,<sup>4</sup> facilitate researcher efforts to engage legal assistance, and ensure the university administration’s conflicts of interest do not interfere with the defence.

**C. University Administrations:** (a) should be prepared to defend research confidentiality not only for ethics reasons but also to defend academic freedom and maintain the integrity of research; (b) should be encouraged to write policies that anticipate what would happen when

<sup>1</sup> Wording here would use some of SSHWC’s material and integrate it with material from the CIHR *Privacy Best Practices* report (see <http://www.cihr-irsc.gc.ca/e/22085.html> ).

<sup>2</sup> The list of topics noted at the US National Institutes of Health Confidentiality Certificate web site as examples includes (but is not limited to): “sexual attitudes, preferences, or practices; the use of alcohol, drugs, or other addictive products; illegal conduct; information that, if released, could reasonably be damaging to an individual's financial standing, employability, or reputation within the community; information that would normally be recorded in a patient's medical record, and the disclosure of which could reasonably lead to social stigmatization or discrimination; information pertaining to an individual's psychological well being or mental health; genetic information.”

<sup>3</sup> This would not be an overly legalistic treatment: SSHWC would limit its advice to the concrete suggestions that, in such cases, researchers should make the point in their proposals that confidentiality is essential, and should ensure there is a clear understanding of confidentiality between them and research participants that is recorded in some non-identifiable way.

<sup>4</sup> These need not be formal legal challenges. For example, the former member of one university REB reported an incident in which the REB was approached by an insurance company who requested information on a participant who was thought to have disclosed information about an accident. They persisted, but so did the REB; eventually the insurance company gave up.

a researcher is named a “person of interest,” and/or a formal legal challenge to the confidentiality of research information occurs.

### **Recommendations to PRE:**

SSHWC recommends that PRE encourage the granting agencies and learned societies and professional associations to do the following:

- 1. Granting Agencies:** (a) as creators of the TCPS and its ongoing steward, should be prepared to assist in defending the standards it articulates in any way possible – e.g., organizationally, financially, as expert witnesses – in order to defend the integrity of the TCPS and the research enterprise and assert the rights of research participants; (b) should consider requiring universities and other institutions who receive agency funding to set aside funds, individually or collectively, for protecting research participants as part of their MOU.
- 2. Learned Societies and Professional Associations:** (a) should continue articulating disciplinary standards regarding confidentiality, file *amicus curiae* briefs and serve as expert witnesses in court on behalf of researchers who assert privilege when third parties seek identifiable research information, and promote the development of statute-based privileges commensurate with researchers’ ethical obligations to protect research participant privacy and confidentiality; (b) should consider articulating discipline-based standards for members who combine research interests with professional responsibilities (e.g., clinical psychologists; research consultants; educators), if these do not exist already, that address the prospective conflicts of interest that can arise from their dual roles and outline appropriate alternatives for researchers to consider when reconciling such conflicts.

#### **4.2.2 The Researcher’s Dilemma**

The current state of Canadian law requires assertions of privilege to be made after-the-fact of one’s research, while pledges to research participants regarding the protection of confidentiality must be made before it begins, and later be maintained, as part of the informed consent process.

Further, the TCPS recognizes that, in theory at least, law and ethics “may lead to different conclusions” (p.i-8). Researchers may face an ethical dilemma because of this and should consider what they would do when and if that divergence were to occur. The consultation document discussed the choices available for researchers in that final instant, which are referred to in the literature as “ethics first” and “law first” approaches. Many submissions focussed on this dichotomy, and offered a whole range of responses – some extolling the virtues of “ethics first,” others affirming the value of “law first,” more arguing that both need to be accommodated, and still others decrying the current state of law that places researchers in the position where they have to make that choice. SSHWC sees this as an instant where, as the TCPS states, “though ethical approaches cannot preempt the application of the law, they may well affect its future development” (p. i-8). The funding agencies have already made clear that the choice between “ethics first” and “law first” approaches lies with the researcher: “If there is a conflict, the researcher must decide on the most acceptable course of action.”<sup>5</sup>

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<sup>5</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>

Misunderstandings are evident in some submissions that see recognition and acceptance of the legitimacy of an “ethics first” approach as somehow advocating the violation of law. As one submission from an individual stated,

[T]he suggestion is made that TCPS should offer ethical guidance on various circumstances in which the legal and ethical requirements regarding privacy and confidentiality appear to diverge. ... [T]his ... could put federal agencies (the Research Councils) into the unhappy situation of advocating breaking the law (albeit for “ethical reasons”). I would suggest that it would be more prudent for the Tri-Council to work toward alleviating contradictions between ethics and the law.

While SSHWC agrees that effort should be expended to try and resolve the discrepancy, there is a difference between “advocating breaking the law” and “not precluding the possibility” that law and ethics may lead to different conclusions. SSHWC affirms the latter and accepts that, in the final instant, researchers of good conscience may choose one or the other. While this is a matter of nuance, it is a vitally important one.

### **Recommendation for SSHWC Action:**

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 those included in the Canadian Psychological Association Code of Ethics (2000), in which Principles IV.17 and IV.18 state that psychologists are expected to:

IV.17 Familiarize themselves with the laws and regulations of the societies in which they work, especially those that are related to their activities as psychologists, and abide by them. If those laws or regulations seriously conflict with the ethical principles contained herein, psychologists would do whatever they could to uphold the ethical principles. 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.

IV.18 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 course of action and the most responsible, knowledgeable, effective, and respectful way to carry it out.

### **4.2.3 Avoiding the Research Equivalent of Caveat Emptor<sup>6</sup>**

In keeping with principles of informed consent, researchers who opt for the “law first” option need to warn prospective participants of this limit to their pledge in situations where disclosure would be harmful to the participant. SSHWC’s major concern in this situation is that researchers who make that choice are clear this does not diminish their obligation to defend research confidentiality “to the full extent permitted by law,” which in part requires them to ensure that any warnings they give do not constitute “waivers of privilege” that undermine their ability to assert privilege on the participant’s behalf.

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<sup>6</sup> A Latin phrase meaning “let the buyer beware.” It refers to the axiom or principle that the buyer alone is responsible for assessing the quality of goods before they are bought.

Submissions that discussed *caveat emptor* agreed that it was an approach to be avoided, but worried that too strong a statement might only serve to undermine participant autonomy. As one submission from an individual explained,

In regard to the *caveat emptor* situation described in 7.3, I have some mixed reactions. On the one hand, I very much agree that there is the serious risk of downloading responsibility to research subjects through confidentiality and privacy escape clauses in informed consent documents. This can well breach trust with participants. On the other hand, a lot depends on the particular circumstances of the research engagement. Let me offer an analogy in this regard. In many areas of life people make agreements with each other that are “subject to” a variety of presumptive conditions (e.g., this product is safe if used in a normal way under usual circumstances). This of course creates an element of uncertainty (what is an abnormal use or unusual circumstances). But if the stakes are reasonable, people can live with this uncertainty since exceptions are generally rare and usually not all that momentous. This may well apply to a range of research involving humans.

**Recommendation for SSHWC Action:**

“*Caveat emptor*” (“let the buyer beware”) in the research domain should be explained in the TCPS as a concept and a caution – an example of where “good ethics” and “respect for human dignity and autonomy” of participants cross into liability management to the detriment of participants. SSHWC proposes to develop wording for inclusion in the TCPS that outlines the concept but leaves it to REBs to determine where the line is and when it is crossed.

**4.2.4 Unanticipated Heinous Discovery**

The term “unanticipated heinous discovery” refers to situations where, out of the blue, a researcher comes across information or a situation so heinous that s/he feels ethically compelled to violate the pledge of confidentiality made in good faith in order to address some higher ethical purpose.<sup>7</sup> Such disclosures are a breach of the duty of confidentiality and the repercussions would be considerable if participants were to feel that researchers could no longer be trusted to keep sensitive information confidential. As one submission from an REB stated,

We also believe that breach of confidentiality carries with it significant implications for the research enterprise, in particular for trust that research subjects have in the research enterprise, and situations where this should occur should be kept to the absolute minimum. As pointed out in the document, the truth is rarely simple and were this to become commonplace, we believe there would be significant adverse implications for research.

SSHWC’s draft guidelines on unanticipated heinous discovery, outlined in the *Reconsidering* discussion paper, acknowledge the diversity of ethics that would collide at the point where a breach of confidentiality is contemplated, and considers the circumstances in which a breach of confidentiality might be permissible in a relationship governed by a duty of confidentiality. The ethical analysis took into account the Supreme Court’s decision-making in *Smith v Jones* [1999], which deals with exactly those issues in a case involving lawyer-client privilege, which the Supreme Court affirms should guide all relationships that involve a duty of confidentiality.

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<sup>7</sup> We distinguish this from what might be called “anticipated” heinous inquiry, i.e., where the researcher sets out to gather information about heinous acts. It would be unethical to begin research about a topic knowing that one would disclose identifiable information to authorities; any pledge of confidentiality could not be said to have been given in good faith.

A key element in the analysis involves the magnitude of an event that might trigger a disclosure. The submissions revealed a lack of knowledge among some researchers and REBs of how extensively disclosures can adversely affect the research process for what the Supreme Court referred to as an “illusion” of safety. For example, one REB talked about the obligation of all citizens to help police and report crime; there are no such obligations in law beyond a small number of mandatory reporting laws, which are considered below. A subcommittee of a learned society discussed the propensity of some REBs to require researchers to take a certain approach when singling out items from standardized tests – such as the “I have considered suicide” item out of the Beck Depression Inventory – while others required researchers to limit confidentiality on that item when it surpasses some criterion value. SSHWC sees such intervention as undermining the validity of the research, in addition to undermining the relationship between researcher and participant.

SSHWC suggests that the criteria outlined in *Smith v Jones* should be outlined in the TCPS as constituting the minimal criteria that *may* trigger a disclosure. These include (1) the prospective harm that might occur must involve serious injury or death; (2) the prospective act must be imminent; and (3) a clear target must be identified. We emphasize “may” – suggesting that a disclosure is permissible under such circumstances, but not a requirement or duty – and concur with the Supreme Court in saying that, if the criteria are surpassed, the only way to deal with such an eventuality in policy is to say that it should be dealt with on a case-by-case basis, preferably by the researcher contacting and discussing the matter with trusted colleagues when and if there is time. More than one submission also noted that the researcher who finds him or her self in such a dilemma should also have access to legal advice if desired; SSHWC agrees.

#### **Recommendation for SSHWC Action:**

SSHWC should formulate wording for inclusion in the TCPS dealing with the issue of unanticipated heinous discovery. The section should begin with a preamble that talks about the considerable value of social research and the great damage that disclosures can bring, which speaks to the need for disclosures to be events that only happen in the most extreme and rare of circumstances. “Extreme circumstances” gets at the question of the threshold that must be exceeded before a disclosure for ethical reasons might be permitted. SSHWC would outline the criteria from *Smith v Jones* [1999] as constituting that minimum bar. SSHWC would limit the suggested wording to saying that, if the bar is met, deciding what to do requires case-by-case consideration. The researcher’s obligation is to consider the alternatives and make ethical choices. If a decision to disclose is made, it should be the most limited disclosure necessary to prevent the harm. Researchers should be expected to seek advice from colleagues, possibly including the REB, if there is time. The REB should try and help ensure that legal advice is available through the institution’s policies should it be needed.

#### **4.2.5 Mandatory Reporting Laws**

The *Reconsidering* discussion paper noted that further research and legal analysis is warranted with respect to mandatory reporting laws, and the submissions concurred. There is no source in the literature we know of that considers the interaction of research and mandatory reporting laws, nor did the submissions offer any.

There appears to be confusion in the literature and in practice about what reporting requirements exist, and how they might be considered in the research context. The TCPS contributes to the confusion when it mentions that there are mandatory reporting laws surrounding “intent to murder” (p. 3-1), when according to SSHWC’s understanding, no such reporting law exists. The

TCPS also talks generically about mandatory reporting rules regarding “child abuse” when, in British Columbia at least, no such law exists; reporting requirements refer instead to “children in need of protection,” which is rather a different concept. Whether provincial or federal, most instances of mandatory reporting laws we know of do not exempt researchers from their provisions. This creates what one submission described as a “conflict of duties” for researchers.

SSHWC believes it would be unethical, and invalid, to ask questions of research participants knowing in advance that certain sought-after answers would be reported – inconsistent with the TCPS dictum that “Researchers should avoid being put in a position of becoming informants for authorities” (p 2.4).

One submission from an REB offered some suggestions for how information about issues that are subject to mandatory reporting laws can be gathered:

The section on mandatory reporting states that it is unethical to directly question subjects about behaviour for which there is a legal obligation to report because it makes the researcher into an informant. It mentions the possibility of gathering such data anonymously. We can think of other instances when it would be ethically acceptable to gather such information: when the individual has already been convicted of the offence, when the individual is on parole after having served a sentence for an offence, when the individual no longer has the infectious disease or is no longer contagious, etc. Research on these topics is valuable to society and the possibilities should not be limited by narrow wording in the TCPS.

In each case the way the difficulty has been bypassed is to take it out of the purview of mandatory reporting laws. We agree that such research can make valuable contributions to our understanding in an area, but the limitations of using only known crimes and convicted criminals – giving us better understanding only of those who are caught – makes it less appealing than research with more comprehensive samples, even if it is better than nothing.

Another submission from an REB explains some of the ethical complexities involved and notes how useful confidentiality certificates would be in addressing the ethics/law conflict.

It is important that REBs understand what the mandatory reporting laws include, what the processes entail, and what the consequences may be. Considerations of who the researcher will be reporting to are important, e.g. to corrupt authorities, or ones who do not value human rights. Researchers must evaluate the harms and benefits of reporting. They must also ensure that research questions will not entrap participants. An ethics first perspective is required. We firmly believe that Confidentiality Certificates, used in the U.S., should be used in Canada. This will ensure that the confidentiality of participants is protected, no matter the research topic.

**Recommendation to PRE:**

SSHWC recommends that PRE encourage the granting agencies to promote ethical and legal analyses that consider how research subject to mandatory reporting laws and the protection of participants can co-exist. SSHWC also encourages the funding agencies and PRE to convey to federal and provincial legislators how such laws might limit research on important and controversial social issues, and to consider how care and research can co-exist.

## 5. Missing Issues

Several submissions offered suggestions of how SSHWC's consideration of ethics issues relevant to the social sciences and humanities might be expanded. In general SSHWC is reluctant to do so given the fact that this would represent new directions that were not identified in *Giving Voice to the Spectrum* (SSHWC 2004) and would require a significant extension of mandate and resources to address comprehensively. As emerging issues they are worthy of consideration, however, and we flag them here to encourage others to take up them up.

### 5.1 Collectivities

One issue that deserves attention involves collectivities and the duties and unique challenges that arise when many people participate in a research project together. Although SSHWC briefly addressed related ethical issues in the context of focus group research, collectivities engage new dimensions beyond the mere presence of others:

[SSHWC needs to] deal with the issue of confidentiality for communities and secondary subjects. These are concerns that REBs grapple with often: when the topic of the research is a community and/or individuals are being asked to talk about others in the community, what are the rights of the secondary subjects and of the community? In the context of this document, what are the rights of the secondary subjects and the community to have the information revealed kept confidential and what are adequate provisions to deliver that confidentiality, given that identities may be guessed even if names are omitted? (Submission from a University REB)

There is a larger problem here in that TCPS does not deal adequately with research involving communities or collectivities. Privacy and confidentiality are issues that arise in these group contexts. I think further work is needed to address them adequately. (Submission from individual)

Other questions come to mind. Under what circumstances should pledges of confidentiality be extended to the identity not only of individuals but of the entire community? What ethical obligations arise, if any, when people make statements about third parties in their community? And although there are a variety of techniques that can be employed to obfuscate the identities of sources within a group, insiders will speculate on identities and, whether accurate or not, these revelations will have repercussions within the group. What are the researcher's responsibilities there? And should we be developing recommendations on this common scenario?

#### **Recommendation for SSHWC Action:**

SSHWC flags confidentiality issues that arise in relation to research with collectivities for further consideration as time and resources warrant.

### 5.2 Privacy Legislation and Secondary Data Bases

A second issue raised among the submissions concerned the use of secondary data bases and the new layer of issues that arise when linkages across different data bases are sought. Particular encouragement was given to consider these issues in light of privacy legislation formulated at federal and provincial levels (e.g., federal PIPEDA legislation, provincial FOIPOP legislation) and their impact on research.

Submissions questioned whether an appropriate balance has been struck when weighing the social benefits that accrue from research using secondary databases versus the right of participants to judge whether each new use of that data should be permitted. Concerns were raised concerning how REBs interpret the TCPS and on the impact that federal and provincial privacy legislation is having, particularly on large-scale health research such as epidemiological study, although these issues are as relevant in the social sciences beyond the health area *per se*. Other questions focussed on apparent inconsistencies among federal policies, e.g., Protection of privacy legislation that mandates data destruction can conflict with SSHRC policy regarding archiving and sharing of publicly funded research data.

The consultation document outlined how citizens have a right to decide whether and when researchers can have access to their lives. The benefits of large-scale research in the health and social science domains are acknowledged. Ethical challenges arise when data bases offer research opportunities that were not anticipated when the original data were gathered. The consultation document suggested those circumstances should not preclude research being done: “[T]he absence of consent does not preclude doing research, and the provision of confidentiality is a key factor that makes any research, and particularly research without explicit consent, ethical.”

The TCPS recognizes the value of such research and offers advice in relation to the considerations involved:

...[W]ithout 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 programmes.

...

Ethics review is thus an important process for addressing this conflict of societal values. The REB plays an important role in balancing the need for research against infringements of privacy and minimizing any necessary invasions of privacy. (TCPS, pp. 3.1-3.2)

But *do* REBs balance individual and social considerations? Several submissions opined that REBs are forgetting the social benefits side of the balance, and, as such, are starting to make large-scale research on existing data bases impossible, for no “ethical” gain. As the President of one academic society stated,

[T]he zealous application of privacy and confidentiality rules favouring individuals defeats legitimate research ends for larger societal benefit....The ideology of the primacy of the individual defeats concern for social goods. Much debate can ensue on this topic, and has preceded this round of consultations. Perhaps some comment on the alternate scenario of application of spurious and overweening policy concerns about existing data might be useful.

One health researcher’s submission described how epidemiological researchers are caught in a catch-22 when agencies and REBs require consent, while prohibiting direct contact with prospective participants in order to secure that consent:

A trend of increasing legislative protection of personal privacy is observable across the developed world. Although well-intentioned, privacy-protecting legislation has greatly impacted public health research. Data collection in public health studies is affected by the prohibition of, or restrictions on, contacting study subjects, and requirements of consent to participate for anonymous statistical research. As is common in early phases of policy change, the interpretation of privacy legislation varies extensively within jurisdictions, because wording of legislation can be subjective or ambiguous.



SSHWC recognizes that research with single data sets with identifiers intact and research that seeks linkages among multiple data sets, which requires some form of linking identifier to work, pose unique challenges. One can understand how citizens – prospective research participants -- might be concerned by the thought of researchers having unfettered access to multiple and linkable data bases without any solid guarantee their confidentiality will be maintained as it is for their interactions with Statistics Canada, for example. In the process of saying that the SSHWC discussion paper would have benefited by consideration of PIPEDA, the submission from a disciplinary ethics advisory committee underlines the importance of data security to citizen confidence in research:

As an example of what might have been missed by not considering the 10 principles [of PIPEDA] is the emphasis in the principles on having policies/procedures and staff training as part of ensuring security of identifiable information. In the recent publication of the Canadian Policy Research Networks, “Understanding Canadians’ Attitudes and Expectations: Citizens’ Dialogue on Privacy and the Use of Personal Health Information for Health Research in Canada,” it is reported that this is one of the factors that builds citizen confidence about the use of their information in health research. (See <http://www.cprn.org/en/doc.cfm?doc=1428> )

SSHWC trusts the authors of privacy legislation did not intend to put the brakes on socially valuable research such as epidemiological study. We see no problem with researchers using anonymous data sets that have no possibility of identification. When it comes to identifiable data sets, however, and where linkages among multiple data sets are sought (which must contain identifiers if they are to allow for the data linkages that open new lines of inquiry) – SSHWC does not see how these can proceed without consent unless meaningful guarantees are in place that individual confidentiality will be preserved.

**Recommendation to PRE:**

SSHWC encourages PRE to recommend to the funding agencies that they make representations to federal and provincial legislators that underline the social importance of research on secondary data bases involving non-identifiable data and to ensure that privacy legislation does not interfere with those possibilities and the social benefits that can result from them.

## **6. Communicating with the Research Community**

In the interests of transparency, openness and accountability, SSHWC believes it is important to directly express our appreciation to Canada’s research communities for their participation in SSHWC’s consultation through publication of this paper, which we hope will continue the dialogue.

**Recommendation to PRE:**

SSHWC recommends that this discussion paper be posted on the PRE/SSHWC web site.

## 7. Appendix: List of Recommendations

### List of Recommendations

*Continuing the Dialogue on Privacy and Confidentiality: Feedback and Recommendations Arising from SSHWC's Recent Consultation  
November 28, 2006*

*For the purpose of given an summary of all recommendations appearing in the report, the list below has bundled the recommendations according to the identified entity to whom the recommendations are addressed.*

#### Recommendations for SSHWC Action:

1. SSHWC proposes to develop wording for inclusion in the TCPS that reaffirms the general principle of confidentiality while noting two exceptions – when confidentiality is out of researcher's control (where confidentiality should be encouraged but the capacity of the researcher to safeguard it is limited); and where the provision of confidentiality would be disrespectful.
2. SSHWC proposes to write wording for the TCPS that mentions the Wigmore criteria and describes in general terms researcher and REB responsibilities to properly anticipate the criteria when participants could be harmed by disclosures that would be of interest to third parties.
3. SSHWC should propose wording for the TCPS that affirms the need for vigilance in the protection of confidentiality, and offers guidelines for researchers, REBs and university administrations. These would include:
  - A. **Researchers:** (a) should incorporate suggested strategies for the protection of confidential information; (b) should anticipate the Wigmore criteria when confidentiality is essential and there would be negative repercussions to the participant if disclosures were to occur; and (c) if they are designated a "person of interest" or there is an actual legal advance made to them (e.g., via subpoena), they should inform the REB and seek legal help.
  - B. **Research Ethics Boards:** (a) should ensure that in cases where confidentiality is essential and a disclosure could harm participants, there is an archival record (e.g., in the proposal) of the fact confidentiality is considered essential for the acquisition of valid data, as well as the REB's recognition and acceptance of that fact; (b) should be prepared to challenge any third party requests for confidential research information, facilitate researcher efforts to engage legal assistance, and ensure the university administration's conflicts of interest do not interfere with the defence.

**C. University Administrations:** (a) should be prepared to defend research confidentiality not only for ethics reasons but also to defend academic freedom and maintain the integrity of research; (b) should be encouraged to write policies that anticipate what would happen when a researcher is named a “person of interest,” and/or a formal legal challenge to the confidentiality of research information occurs.

4. 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 those included in the Canadian Psychological Association Code of Ethics (2000), in which Principles IV.17 and IV.18 state that psychologists are expected to:

IV.17 Familiarize themselves with the laws and regulations of the societies in which they work, especially those that are related to their activities as psychologists, and abide by them. If those laws or regulations seriously conflict with the ethical principles contained herein, psychologists would do whatever they could to uphold the ethical principles. 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.

IV.18 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 course of action and the most responsible, knowledgeable, effective, and respectful way to carry it out.

5. “*Caveat emptor*” (“let the buyer beware”) in the research domain should be explained in the TCPS as a concept and a caution – an example of where “good ethics” and “respect for human dignity and autonomy” of participants cross into liability management to the detriment of participants. SSHWC proposes to develop wording for inclusion in the TCPS that outlines the concept but leaves it to REBs to determine where the line is and when it is crossed.
6. SSHWC should formulate some wording for inclusion in the TCPS dealing with the issue of unanticipated heinous discovery. The section should begin with a preamble that talks about the considerable value of social research and the great damage that disclosures can bring, which speaks to the need for disclosures to be events that only happen in the most extreme and rare of circumstances. “Extreme circumstances” gets at the question of the threshold that must be exceeded before a disclosure for ethical reasons might be permitted. SSHWC would outline the criteria from *Smith v Jones* [1999] as constituting that minimum bar. SSHWC would limit the suggested wording to saying that, if the bar is met, deciding what to do requires case-by-case consideration. The researcher’s obligation is to consider the alternatives and make ethical choices. If a decision to disclose is made, it should be the most limited disclosure necessary to prevent the harm. Researchers should be expected to seek advice from colleagues, possibly including the REB, if there is time. The REB should try and help ensure that legal advice is available through the institution’s policies should it be needed.

7. SSHWC flags confidentiality issues that arise in relation to research with collectivities for further consideration as time and resources warrant.

## **Recommendations to PRE:**

1. SSHWC recommends PRE convey to SSHRC and the other granting agencies SSHWC's view, reaffirmed in the submissions, of the value of research that attempts to better understand research ethics issues from participants' perspectives. The Working Committee also hopes that SSHRC and the other granting agencies might consider allocating dedicated funding to encourage members of the research community to do research that contributes to those understandings.
2. The consultation revealed diverse support across the research community for the development of statute-based protections for research participant confidentiality along the lines of US-based "confidentiality certificates" and "privacy certificates." SSHWC asks that PRE convey these affirmations to the Presidents of the granting agencies along with its recommendation that the Presidents more actively explore this legislative alternative for further discussion with their respective Ministers.
3. SSHWC recommends that PRE encourage the granting agencies to promote ethical and legal analyses that consider how research subject to mandatory reporting laws and the protection of participants can co-exist. SSHWC also encourages the funding agencies and PRE to convey to federal and provincial legislators how such laws might limit research on important and controversial social issues, and to consider how care and research can co-exist.
4. An analysis of the implications of federal PIPEDA and provincial FOIPOP legislation on the research enterprise is beyond the capacity of SSHWC to undertake. Such analyses would, however, be very useful as a prerequisite to making recommendations as to how research possibilities and privacy rights might be balanced and mutually accommodated. Accordingly, SSHWC recommends that PRE encourage CIHR and SSHRC to promote such analyses through existing or prospective grant programmes.
5. SSHWC encourages PRE to recommend to the funding agencies that they make representations to federal and provincial legislators that underline the social importance of research on secondary data bases involving non-identifiable data and to ensure that privacy legislation does not interfere with those possibilities and the social benefits that can result from them.
6. SSHWC recommends that PRE encourage the granting agencies and learned societies and professional associations to do the following:
  1. **Granting Agencies:** (a) as creators of the TCPS and its ongoing steward, should be prepared to assist in defending the standards it articulates in any way possible – e.g., organizationally, financially, as expert witnesses – in order to defend the integrity of the TCPS and the research enterprise and assert the rights of research participants; (b) should consider requiring universities and other institutions who

receive agency funding to set aside funds, individually or collectively, for protecting research participants as part of their MOU.

2. **Learned Societies and Professional Associations:** (a) should continue articulating disciplinary standards regarding confidentiality, file *amicus curiae* briefs and serve as expert witnesses in court on behalf of researchers who assert privilege when third parties seek identifiable research information, and promote the development of statute-based privileges commensurate with researchers' ethical obligations to protect research participant privacy and confidentiality; (b) should consider articulating discipline-based standards for members who combine research interests with professional responsibilities (e.g., clinical psychologists; research consultants; educators), if these do not exist already, that address the prospective conflicts of interest that can arise from their dual roles and outline appropriate alternatives for researchers to consider when reconciling such conflicts.

7. SSHWC recommends that this discussion paper be posted on the PRE/SSHWC web site.