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# Reconsidering Privacy and Confidentiality in the TCPS: A Discussion Paper

**Social Sciences and Humanities Research Ethics  
Special Working Committee (SSHWC)**

**9 October 2005**

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## Table of Contents

<b>1. THE PURPOSE OF THIS DISCUSSION PAPER.....</b>	<b>4</b>
<b>2. RESPECT FOR PRIVACY AND CONFIDENTIALITY.....</b>	<b>5</b>
2.1 PRIVACY AND CONFIDENTIALITY AS “GUIDING PRINCIPLES” OF ETHICS .....	5
2.2 PRIVACY FROM RESEARCH(ERS).....	5
2.3 PROTECTING PRIVACY THROUGH CONFIDENTIALITY .....	6
<b>3. ARTICULATING PRIVACY AND CONFIDENTIALITY ISSUES .....</b>	<b>6</b>
3.1 UNDERSTANDING THE IMPLICATIONS OF A “SUBJECT-CENTERED PERSPECTIVE” TO PRIVACY AND CONFIDENTIALITY ISSUES .....	7
3.2 ARTICULATING A RANGE OF APPROACHES TO CONFIDENTIALITY ISSUES .....	7
3.3 CONSIDERING THE RELATIONSHIP BETWEEN ETHICS AND LAW .....	7
<b>4. A “SUBJECT-CENTERED PERSPECTIVE” ON PRIVACY AND CONFIDENTIALITY .....</b>	<b>7</b>
4.1 SSHWC RESEARCH INITIATIVE .....	7
4.2 SOME INTERIM PRINCIPLES .....	8
<b>5. APPROACHES TO CONFIDENTIALITY .....</b>	<b>8</b>
5.1 WHEN CONFIDENTIALITY IS UNNECESSARY .....	8
5.2 WHEN CONFIDENTIALITY IS FREELY WAIVED BY THE PARTICIPANT .....	9
5.3 WHEN CONFIDENTIALITY IS OUT OF THE RESEARCHER’S CONTROL.....	9
5.4 WHEN CONFIDENTIALITY IS UNDESIRABLE OR DISRESPECTFUL .....	9
5.5 WHEN CONFIDENTIALITY IS ESSENTIAL .....	9
5.6 THE DECISION TO DISCLOSE PERSONAL INFORMATION RESTS WITH THE PARTICIPANT.....	10
<b>6. ETHICS AND LAW .....</b>	<b>10</b>
6.1 EXISTING AND POSSIBLE PROTECTIONS FOR PARTICIPANT PRIVACY AND RESEARCH CONFIDENTIALITY IN LAW .....	11
6.1.1 Statute-based Protections at Statistics Canada and for “Deemed Researchers” .....	11
6.1.2 Possible Protections in Common Law through the Wigmore Criteria.....	11
6.1.3 Statute-based Protections for Some Canadians Doing Research in the United States .....	12
6.1.4 Unknown Levels of Protection from “Protection of Privacy” Legislation .....	12
6.2 POSSIBLE SOURCES OF CONFLICT BETWEEN ETHICS AND LAW .....	12
6.2.1 Criminal Prosecutions and Civil Litigation .....	12
6.2.2 Unanticipated “Heinous Discovery” .....	13
6.2.3 Mandatory Reporting Laws.....	13
<b>7. CRIMINAL PROSECUTIONS AND HIGH STAKES LITIGATION .....</b>	<b>13</b>
7.1 PROTECTING CONFIDENTIALITY IS A SHARED AND PROACTIVE RESPONSIBILITY .....	14
7.1.1 Researchers.....	14
7.1.2 Research Ethics Boards .....	15
7.1.3 University Administrations.....	15
7.1.4 The Granting Agencies.....	15
7.1.5 Disciplinary and Professional Associations.....	15
7.2 THE RESEARCHER’S DILEMMA .....	16
7.2.1 An “ethics-first” approach.....	16
7.2.2 A “law-first” approach.....	17
7.3 AVOIDING A RESEARCH EQUIVALENT OF CAVEAT EMPTOR.....	17
7.3.1 Informing Participants .....	18
7.3.2 Avoiding Waivers of Privilege.....	18
7.3.3 Ensuring No Harm Can Result.....	19

<b>8. UNANTICIPATED HEINOUS DISCOVERY .....</b>	<b>19</b>
8.1 THE TRUTH IS RARELY SIMPLE .....	19
8.2 WHAT PROSPECTIVE HARM MIGHT MAKE VOLUNTARY DISCLOSURE PERMISSIBLE? .....	20
8.3 ENDURING OBLIGATIONS TO THE PARTICIPANT .....	21
8.4 SHOULD A “HEINOUS DISCOVERY” WARNING BE PART OF INFORMED CONSENT? .....	21
8.5 A DRAFT POLICY .....	22
<b>9. MANDATORY REPORTING LAWS.....</b>	<b>23</b>
9.1 DIVERSE APPROACHES TO MANDATORY REPORTING .....	23
9.2 DIRECT QUESTIONING OF REPORTABLE BEHAVIOUR .....	24
9.3 WHERE TOUCHING ON MANDATORY REPORTING LAWS IS PLAUSIBLE.....	24
9.4 WHEN THIRD PARTIES ARE AFFECTED .....	24
<b>10. AFFECTING THE DEVELOPMENT OF LAW THROUGH ETHICAL APPROACHES.....</b>	<b>25</b>
<b>11. SELECTED BIBLIOGRAPHY.....</b>	<b>25</b>

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## 1. The Purpose of this Discussion Paper

This discussion paper reflects SSHWC's thinking to date about privacy and confidentiality issues in the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS). It contains preliminary discussions and some draft proposals that address privacy and confidentiality issues not yet considered in the TCPS that were identified as matters of concern during the consultations that culminated in SSHWC's earlier report entitled *Giving Voice to the Spectrum* (2004).<sup>1</sup> It does not purport to identify or resolve all outstanding issues related to privacy and confidentiality, but does speak to some of the more significant concerns raised by the many qualitative and interpretive field-based researchers who participated most actively in our consultations with Canada's Social Science and Humanities research communities, and whose perspectives and approaches have yet to be fully recognized in the TCPS.

The objective of this discussion paper is not to put forth final policy recommendations but to offer proposals and identify some options that have been brought forward to date. We do this in the interest of promoting further discussion by the research community – wondering not only whether we have adequately captured the diversity of views persons from the social sciences and humanities would bring to the issues, but also how the principles we identify would play out in other disciplines and perspectives - - anticipating this will lead to the identification of other alternatives that will need to be considered during the dialogue. SSHWC's development and recommendation of specific policy options and proposals for changes to the TCPS will arise from that dialogue, and will be the subject of future reports and consultations.

We encourage comments and reactions to this report from researchers, research ethics administrators, REB members and other interested parties from the social sciences and humanities and other disciplines that we can consider prior to drafting recommendations for consideration by the Interagency Advisory Panel on Research Ethics (PRE) regarding privacy and confidentiality issues.<sup>2</sup>

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<sup>1</sup> *Giving Voice to the Spectrum* is available online at <http://www.pre.ethics.gc.ca/english/workgroups/sshwc/SSHWCVoiceReportJune2004.pdf>

<sup>2</sup> Comments can be sent to SSHWC at [sshwc@pre.ethics.gc.ca](mailto:sshwc@pre.ethics.gc.ca)

## 2. Respect for Privacy and Confidentiality

### 2.1 Privacy and Confidentiality as “Guiding Principles” of Ethics

“Respect for Privacy and Confidentiality” is listed as a “guiding principle” in the TCPS (MRC *et al* 1998) and described thus:

**Respect for Privacy and Confidentiality:** Respect for human dignity also implies the principles of respect for privacy and confidentiality. In many cultures, privacy and confidentiality are considered fundamental to human dignity. Thus, standards of privacy and confidentiality protect the access, control and dissemination of personal information. In doing so, such standards help to protect mental or psychological integrity. They are thus consonant with values underlying privacy, confidentiality and anonymity respected. (p. i.5)

A more detailed articulation of privacy and confidentiality rights appears in Section 3 of the TCPS. The right of persons to privacy is grounded in the core ethical principle of respect for the dignity of persons, as well as in the legal status it has been accorded in Supreme Court decision-making and both federal and provincial protection of privacy legislation.

The current preamble to the TCPS’s Section 3 regarding privacy has two aspects to it. One is the right of privacy that people have from research and researchers, i.e., the right to decline participation. The second is the right of those who *do* participate in research to have their privacy protected by the researcher through the latter’s provision of anonymity or confidentiality.<sup>3</sup>

### 2.2 Privacy from Research(ers)

Notwithstanding the social mandate that university researchers have to understand all aspects of society, the ethical and legal claim of people to privacy implies that researchers cannot gather whatever information they wish about whomever they wish whenever and wherever they wish. In relation to that invasiveness, the TCPS emphasizes the desirability of informed consent wherever possible, so that prospective participants can choose whether to let researchers into their lives on terms that are negotiated, or at least understood. That is particularly so when the data are gathered and maintained so as to be identifiable as to their source [hereafter referred to as “identifiable data”; their opposite would be “unidentifiable,” “anonymized” or “anonymous” data]. However, the 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. As explained in the TCPS,

...[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.

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<sup>3</sup> Anonymity means the data are unidentifiable as to source because no names or other unique identifiers are attached. Confidentiality refers to situations where identifying information is known, but not revealed. Gathering only anonymous data (i.e., data that do not include identifying personal information) is the easiest way to protect participants, although this is not always either possible or desirable. If possible, a “next best” alternative is to “anonymize” the data at the earliest opportunity, i.e., to remove identifiers from transcripts or records. Failing the feasibility of those two options – and there are many reasons why data may need to be gathered and retained in identifiable form – then the provision of confidentiality becomes paramount.

Historically, the benefits of the confidential research use of personal data have been substantial. Two of many such examples are: the identification of the relationship between tobacco and lung cancer; and the use of employment or educational records to identify the benefits or harms of various social factors. In the last two decades, larger data bases and newer techniques have improved the capacity of researchers to evaluate the delivery of services and the outcomes of many procedures and products. These studies have contributed to more responsive and efficient service delivery in areas such as health, education, safety and the environment.

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. (pp. 3.1-3.2)

When informed consent is sought, and the REB has approved the representations on which that consent will be based, prospective participants who are competent can decide for themselves whether they are prepared to allow whatever infringement of their privacy the proposed research involves. When it is not, the REB, guided by a subject-centered perspective, and with respect for the academic freedom of researchers, will undertake to consider whether the approach proposed by the researcher is consistent with disciplinary standards and the policy statement.

### **2.3 Protecting Privacy through Confidentiality**

In the event the prospective participant decides to take part in the research, or the REB provides clearance even though the prospective participant has not been asked, the TCPS makes clear that a duty befalls the researcher to protect rights to privacy by ensuring any identifiable information remains strictly confidential unless directed otherwise by a research participant:

Information that is disclosed in the context of a professional or research relationship must be held confidential. Thus, when a research subject confides personal information to a researcher, the researcher has a duty not to share the information with others without the subject's free and informed consent. Breaches of confidentiality may cause harm: to the trust relationship between the researcher and the research subject; to other individuals or groups; and/or to the reputation of the research community. Confidentiality applies to information obtained directly from subjects or from other researchers or organizations that have a legal obligation to maintain personal records confidential. In this regard, a subject-centred perspective on the nature of the research, its aims and its potential to invade sensitive interests may help researchers better to design and conduct research. A matter that is public in the researcher's culture may be private in a prospective subject's culture, for example.

There is a widespread agreement about the rights of prospective subjects to privacy and the corresponding duties of researchers to treat private information in a respectful and confidential manner. Indeed, the respect for privacy in research is an internationally recognized norm and ethical standard. It has been enshrined in Canadian law as a constitutional right and protected in both federal and provincial statutes. Model voluntary codes have also been adopted to govern access to, and the protection of, personal information. (MRC *et al* 1998, p.3-1)

## **3. Articulating Privacy and Confidentiality Issues**

On matters described above, SSHWC is in accord with the current section of the TCPS regarding Privacy and Confidentiality. However, three priority areas were flagged for further development during the consultations reported in *Giving Voice to the Spectrum* (SSHWC, 2004) and are the foci of this discussion paper:

### **3.1 Understanding the Implications of a “Subject-Centered Perspective” to Privacy and Confidentiality Issues**

In Section 4 we urge further development related to a subject-centered perspective, offer some interim proposals, and encourage researchers and those who participate in their research to contribute to this important area.

### **3.2 Articulating a Range of Approaches to Confidentiality Issues**

SSHWC suggests the TCPS should include a clearer articulation of the range of issues that researchers and REBs should consider when determining what approach to confidentiality is most appropriate in their particular context. A preliminary description of the range of possibilities is included in Section 5.

### **3.3 Considering the Relationship Between Ethics and Law**

Although we always hope and should aspire to be both ethical and legal, the TCPS recognizes that occasions may arise when law and ethics “may lead to different conclusions” (p.i-8).

Section 6 outlines ways in which research confidentiality and law appear to coincide through legal mechanisms that do or may protect research participants, as well as areas in which the ethics and law of research confidentiality may come into conflict.

Sections 7 through 9 consider areas of prospective ethics-law conflict in greater detail, and outline a range of alternatives and obligations that researchers can consider when designing their research, and that REBs should consider when scrutinizing their proposals.

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

Although the TCPS requires researchers and REBs to adopt a “subject-centered perspective” when generating and evaluating research proposals, the 1998 TCPS contains no guidelines for researchers and/or REBs as to what we know about those perspectives, how they might be relevant across different methods and approaches, and what ethics issues arise from maintaining that principle across diverse areas of research. Despite its centrality to the research design and ethics review process, there is little empirical evidence to date on this topic; the literature begs for further development.

### **4.1 SSHWC Research Initiative**

Toward that end, SSHWC is undertaking exploratory research regarding participants’ perspectives on confidentiality issues through a “Participants’ Perspectives” sub-group, and will incorporate relevant findings into future Working Reports and recommendations. SSHWC encourages other researchers to consider these issues in the context of their own research domains, and we ask any researchers reading this discussion paper to share with us their knowledge regarding the perspectives of participant populations with whom they work – whether from their own direct discussions and observations or

through literature of which they are aware – particularly with respect to their expectations regarding privacy and confidentiality, and/or to encourage participants to contact us directly.<sup>4</sup>

## 4.2 Some Interim Principles

Given the dearth of literature related to a subject-centered perspective, understanding participant perspectives regarding confidentiality and considering their implications for ethics review will not occur overnight. In the interim, we offer the following principles for researchers and REBs to consider, and would appreciate the research community's comments on their ethical appropriateness and feasibility:

- i. As a general principle, the greater the social distance between the participant group and the researcher(s), the greater the effort that should be expended to solicit information regarding participant perspectives on confidentiality provisions that would be meaningful and appropriate to the participants in the proposed research context.
- ii. As a general principle, the less the experience of the most senior researcher with the participant group, the greater the effort that should be expended to solicit participant perspectives regarding confidentiality provisions that would be meaningful and appropriate to the participants in the proposed research context.
- iii. When REBs do not have members who have had direct experience with the proposed participant group, they should seek out and give significant weight to the understandings of researchers who have that experience, including, if warranted by his/her personal experience, the researcher making the application.<sup>5</sup>

## 5. Approaches to Confidentiality

One implication of incorporating a “subject-centered perspective” in relation to privacy and confidentiality issues is the need to consider the range of relations in which they arise. While ensuring the provision of confidentiality with respect to the source of any information gathered is the appropriate default assumption failing any agreement to the contrary – both because confidentiality is a core ethical principle and because in most cases any waiving of confidentiality can only be done by the participant -- situational parameters and the need to consider subject-centered perspectives may lead to other resolutions regarding the provision of confidentiality. Researchers should identify in their proposals which option applies to their research.

Researchers and research administrators who have other examples and approaches to suggest are encouraged to share them with SSHWC.

### 5.1 When Confidentiality is Unnecessary

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<sup>4</sup> The committee's interests include but go beyond issues of privacy and confidentiality to include other issues and principles – access and recruitment, conflict of interest, informed consent, post-research follow-up, and so on – that are the focus of reports being prepared by other subgroups of SSHWC. Research participants can contact us directly at [sshwc@pre.ethics.gc.ca](mailto:sshwc@pre.ethics.gc.ca) to initiate a dialogue that would be most helpful in our preliminary work in preparation for a web-based survey we expect to have operational later in 2005.

<sup>5</sup> Provisions for *ad hoc* membership for the consideration of unique proposals are outlined in the TCPS on p.1-4. The benefits of including the researcher in the dialogue are noted on p.1-9 in the discussion following Article 1.9.



In some instances, a provision of confidentiality may be *unnecessary*, e.g., when the human participant is a public figure or official spokesperson for an organization; when the data are observable by anyone in a public setting; and so on. Nonetheless, researchers should normally refrain from naming individuals in their written reports and other publications unless the participant agrees to be named and/or other principles – for example, the accountability of public figures – apply. In some instances, such research would fall under the exemptions from ethics review that are listed in the TCPS.<sup>6</sup>

## **5.2 When Confidentiality is Freely Waived by the Participant**

A provision of confidentiality may be freely waived by the participant when the information sought is of the sort they would freely share with the researcher or anyone else, e.g., when a researcher is interviewing persons in regards to their attitudes on a topic that people might talk about at a party or with any stranger and the participant does not care whether confidentiality is observed. In such a situation, a default expectation of confidentiality should nonetheless prevail. Researchers should be circumspect about naming individuals or sharing information with other individuals in the research, and would normally anonymize any written analyses or results unless given specific permission to name individuals, or the participant specifically asks to be named. In the latter case, researchers should consider, but not automatically grant, such a request. The role of the REB would be to ensure that any waiving of confidentiality is done freely, and that no undisclosed harms can befall the participant in the event of disclosure.

## **5.3 When Confidentiality is Out of the Researcher's Control**

In other situations it may be *difficult* to guarantee confidentiality, such as when its provision is beyond the researcher's direct ability to control. For example, researchers who do "focus group" interviews where participants are sharing their views in this quasi-public forum can understand and respect the sensibilities of participants in relation to their preferences for confidentiality outside the group setting in any written materials arising from the interviews, but they have no direct control over what the other participants in the group interview may say outside the research setting. However, researchers in this situation may use the opportunity to discuss confidentiality considerations, educate participants about its importance to the research process, and encourage them to respect the confidentiality of others just as they would hope others would respect theirs. In rare instances, researchers might consider asking participants to agree to or even to sign non-disclosure agreements.

## **5.4 When Confidentiality is Undesirable or Disrespectful**

In a fourth set of situations, providing confidentiality may be *undesirable*, or even *disrespectful*. In oral history, for example, there is a strong and respectful tradition of naming participants. The same is true of studies involving Indigenous Elders, where naming the individual, with his or her permission, is often essential to showing appropriate respect.

## **5.5 When Confidentiality is Essential**

Finally, in many situations confidentiality is *essential* to the generation of valid data because prospective research participants will only share personal information, and society can only benefit from that information, if they are convinced the researcher will not reveal their sources and that they will not be

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<sup>6</sup> See Article 1.1(c) on p.1-1.

harmed because of their participation.<sup>7</sup> In some instances this may be because of social norms respecting the kinds of information that should remain private; in other instances it may be because any divulging of identifiable information can have serious repercussions for the individual within and/or outside his/her immediate family or other social group.

## 5.6 The Decision to Disclose Personal Information Rests With the Participant

Researchers submitting proposals should articulate which of the above scenarios applies to their work, and the basis for their view, which presumably will be grounded in disciplinary standards and some indication of the prospective participants' perspectives in relation to confidentiality.

Recognition that the provision of confidentiality is not always essential for gathering data should not undermine the general expectation that identifiable information that arises from the researcher-participant relationship is confidential unless provisions to the contrary are clearly established and freely agreed to by the participant<sup>8</sup>: “[W]hen a research subject confides personal information to a researcher, the researcher has a duty not to share the information with others without the subject’s free and informed consent” (TCPS, p.3-1). Failing arrangements to the contrary, researchers have a duty of confidentiality to research participants and should act in a manner consistent with that duty.

When the information gathered is such that the participant would be harmed by disclosure, the decision of whether to disclose or not lies with the participant, and can only be waived by him or her.<sup>9</sup> Researchers cannot make participation in their research contingent on the prospective participant’s waiving privilege or any other legal rights they do or might have.

## 6. Ethics and Law

Our ethical obligations to participants with respect to privacy and confidentiality intermingle with law in a variety of ways, some of which have been considered in the peer-reviewed literature, while others await more detailed consideration.

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<sup>7</sup> A non-exhaustive list of the range of areas in which confidentiality is considered essential for the gathering of valid data can be seen in the list of areas for which researchers in the United States can acquire statute-based protections in the form of “privacy certificates” and “confidentiality certificates.” The list 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>8</sup> The situation here is comparable to lawyer-client privilege, which is a “class” privilege recognized in common law by the Supreme Court. Confidentiality is considered “essential” for the lawyer-client relationship even though in many specific instances – preparing routine house transfer-of-ownership documents, for example – the relationship could easily transpire without a guarantee of confidentiality.

<sup>9</sup> This recognition that confidentiality can only be waived by the participant and that it must be done freely appears in numerous Codes of Ethics and statutes that transcend disciplines and countries. It is also consistent with Protection of Privacy legislation that places the control of identifiable information with the person(s) who are named, and with duties of confidentiality concerning other forms of privilege (e.g., the privilege attached to the lawyer-client relationship is the privilege of the client, *not* the lawyer).

Although one would hope that ethics and law will always coincide, the TCPS recognizes that, in the current state of law, “legal and ethical approaches to issues may lead to different conclusions” (TCPS, p.i-8). This is certainly so in the confidentiality area, where the law and legal decision-making with respect to the confidentiality of research data varies from clear to encouraging to ambiguous. The absence in Canadian law of any clear statute-based protections for most research participants – the available protections we know of at this point are available only after the fact of a specific legal challenge being mounted -- creates the possibility of an ethics-law divergence.

In order to better negotiate consistencies and understand divergences between ethics and law, we suggest the TCPS should include a discussion of where and how these divergences might arise, how they might be anticipated, and what ethical obligations accrue in each situation. A preliminary discussion of those issues appears below. Researchers reading this report are encouraged to send their comments on the adequacy and comprehensiveness of the approaches suggested to SSHWC.

## **6.1 Existing and Possible Protections for Participant Privacy and Research Confidentiality in Law**

Understanding of the law and its intersection with research confidentiality in Canada is still evolving, but has developed considerably within the last decade during which initial threats to confidentiality from third parties have appeared in Canada and competing interests – between privacy rights and concerns regarding security or previously “hidden” social problems such as child abuse and sexual abuse, for example – have come to the fore. We begin by considering ways that law and ethics may coincide by virtue of existing or prospective legal protections for research participant privacy and confidentiality.

### ***6.1.1 Statute-based Protections at Statistics Canada and for “Deemed Researchers”***

One group of researchers and participants who have blanket statute-based legal protection for their research confidences are researchers at Statistics Canada and their participants, who have a statutory privilege conferred on their work via the *Statistics Act*. Recently, this protection has been expanded in a manner consistent with the *Act* by allowing Statistics Canada to designate certain academic researchers “deemed researchers” and allow them access to identifiable (individual-level) data under certain prescribed and controlled conditions, which includes extension of both the obligations and the privilege of the *Statistics Act* to the deemed researcher.<sup>10</sup>

Although there are no blanket statute-based protections that create privileges for Canadians who participate in research not conducted under the auspices of Statistics Canada, there are several existing or possible sources of protection for research confidentiality that do or may apply in particular cases.

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

Research participants may be protected in common law through researchers asserting a researcher-participant privilege in court. In Canada, this is done by invoking the Wigmore criteria, a common law test the Supreme Court has identified as the appropriate vehicle for assertion of privilege on a case-by-case basis. In making such a claim, the onus is on the person claiming the privilege – the researcher, in this case, on behalf of the participant – to demonstrate that s/he has met the criteria.<sup>11</sup>

<sup>10</sup> For a description of the “deemed researcher” program see <http://www.statcan.ca/english/rdc/index.htm>

<sup>11</sup> See, for example, Sopinka, J., Lederman, S.N., and Bryant, A.W. (1992). *The law of evidence in Canada*. Toronto: Butterworths. The Wigmore criteria are: (1) The communication 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

### **6.1.3 Statute-based Protections for Some Canadians Doing Research in the United States**

Canadian researchers doing “health” research in the United States, whether funded by the U.S. National Institutes of Health or not, and researchers doing criminological research in the United States that is funded by the U.S. National Institute of Justice, are eligible to apply under certain circumstances for statute-based confidentiality protections in the form of “Certificates of Confidentiality” (for health research)<sup>12</sup> or “Privacy Certificates” (for criminological research)<sup>13</sup> that can be used to protect their data while it is in the United States. Because equivalent protections are not available in Canada, it may be necessary for any identifiable data gathered under these provisions to remain in the United States.<sup>14</sup>

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

Another area of legislation that may provide some degree of protection for research participants is the Freedom of Information and Protection of Privacy legislation that now exists federally and in every Province.<sup>15</sup> But while the peer-reviewed literature now includes discussion on the prospective applicability of the Wigmore criteria and of the U.S. confidentiality certificates and privacy certificates to research,<sup>16</sup> we are unaware of any similar discussion in relation to privacy legislation.<sup>17</sup>

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

There are at least three areas of potential conflict between the law and the ethical duty of confidentiality to research participants:

### **6.2.1 Criminal Prosecutions and Civil Litigation**

Crown prosecutors, Senate Committees and various public bodies can subpoena researchers to testify about crimes and/or other offences research participants may have revealed to the researcher. Coroners also can subpoena researchers who they think might have information relevant to an inquest. Similarly, non-governmental third parties can subpoena researchers to testify about issues arising in high stakes litigation. These situations are considered in Section 7 below.

the relation between the parties; (3) The relation must be one in which 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 litigation.

<sup>12</sup> For information about confidentiality certificates, see <http://grants.nih.gov/grants/policy/coc/index.htm>.

<sup>13</sup> For information about privacy certificates, see <http://www.ojp.usdoj.gov/nij/humansubjects/>.

<sup>14</sup> That said, concerns exist among U.S. researchers over the implications of the *Patriots Act* that was passed in the U.S. in 2001 that, in s.215, gives the U.S. Federal Bureau of Investigation pervasive and secret power of access to information for any “investigation to protect against international terrorism or clandestine intelligence activities.” It is illegal for those receiving the orders for disclosure even to inform their superiors that such an order has been received and/or to inform those whose information was taken whether and what disclosure was made. These extraordinary powers appear to create significant potential for abuse.

<sup>15</sup> We flag this area because, in the United States, both Certificates of Confidentiality and Privacy Certificates arose out of legislation mandating participant privacy in research funded or otherwise sponsored by the U.S. federal government.

<sup>16</sup> For a researcher and ethics-based perspective, see, for example, Palys and Lowman (2000); for a formal legal perspective, see Jackson and MacCrimmon (1999).

<sup>17</sup> In the Spring of 2005, SSHRC announced the availability of \$120,000 for research funding to address issues such as these, and we hope that some of the proposals submitted and funds allocated involve consideration of that issue. In the interim, any observations on this topic that researchers and/or legal advisors wish to share with SSHWC prior to preparation of our final report would be most appreciated.

### **6.2.2 Unanticipated “Heinous Discovery”**

Unanticipated heinous discovery occurs when researchers serendipitously learn about prospective harm to an identifiable target that is outside the expected scope of their research inquiry and is so serious if it were to occur that they feel ethically compelled to violate the promise of confidence they offered in good faith in order to prevent the harm. Prospective conflicts with law arise because they may be held liable for harm to third parties they could have prevented, as well as for harms they may create if their reading of the situation is incorrect and their allegation false. Ethical issues arising from this possibility are considered in Section 8 below.

### **6.2.3 Mandatory Reporting Laws.**

Although there is no general legal obligation for researchers to report crime they hear about in relation to their research, some specific mandatory reporting laws have been enacted that do not exempt researchers. These vary by jurisdiction, but may include, for example, elder abuse, child abuse or “children in need of protection,” and/or spousal assault. Also, some provinces may enact mandatory reporting laws that pertain to members of particular professions. See Section 9 below for a discussion on the ethical implications of these laws for researchers.

In general, mandatory reporting laws and unanticipated heinous discovery involve situations where the researcher's violation of confidentiality would be a matter of his or her own initiative, independent of any direct external compulsion, because in many cases it is unlikely anyone other than the researcher will know what the researcher knows. In contrast, subpoenas create the threat of compelled revelation. Depending on the kind of research they are conducting, researchers could find themselves confronting dilemmas in any of these three areas. Historically, in the U.S. at least, it is the first category — involving the possibility of subpoena and orders for disclosure — that have received the greatest attention, perhaps because they are the most visible. In Canada there have been considerably fewer visible conflicts thus far, all of which have fallen in the first category.<sup>18</sup> However, some would argue that the most pervasive contemporary issue in ethics and law is the impact on research of mandatory reporting laws.

In the sections that follow, we discuss ethical issues that arise in each of the three areas and offer interim resolutions or alternatives SSHWC has developed and/or seen advanced in the literature. We welcome any readers of this interim report who would like to advance alternative approaches to contact SSHWC at [sshwc@pre.ethics.gc.ca](mailto:sshwc@pre.ethics.gc.ca).

## **7. Criminal Prosecutions and High Stakes Litigation**

Third parties may attempt to use legal force – typically via subpoena -- in an effort to secure, for their own purposes, identifiable research information that was gathered in confidence:

**In the realm of criminal law:** Crown prosecutors, Senate Committees and various public bodies can subpoena researchers to testify about crimes and/or other offences research participants may have revealed to the researcher. Coroners also can subpoena researchers who they think might have information relevant to an inquest.<sup>19</sup>

<sup>18</sup> See, for example, Cecil and Wetherington (1996) and Palys and Lowman (2000).

<sup>19</sup> Most of these subpoenas arose in the United States. We have translated all legal references to the Canadian context, e.g., by referring to “Crown Prosecutors” rather than “District Attorneys.” Also, a major source of

**In the realm of civil law:** Non-governmental third parties can subpoena researchers to testify about issues arising in high stakes litigation.

## **7.1 Protecting Confidentiality is a Shared and Proactive Responsibility**

Confidentiality is a core ethical principle in the TCPS and is essential to the acquisition of valid data in many areas. When third parties attempt to acquire research information provided in confidence, they exploit the existence of information that in all likelihood would not have existed save for participants' trust in the researcher and belief in the integrity of the research enterprise. As the TCPS recognizes, "Breaches of confidentiality may cause harm: to the trust relationship between the researcher and the research subject; to other individuals or groups; and/or to the reputation of the research community." (p.i-8). Third party challenges to confidentiality should be resisted vigorously. The TCPS already recognizes this obligation, noting that, as a minimal standard, researchers are "honour-bound" to protect "to the extent possible within the law" the confidentiality they have pledged, and that researchers' institutions should support them (p.3-2).

However important these affirmations, the ethical obligation to protect research participants, research confidentiality and the integrity of the research enterprise is best accomplished if resistance is seen as more than a reactive possibility. Doing so effectively is a shared responsibility that also requires prevention and prepared response. The TCPS thus should express not only the onus of responsibility on researchers, REBs and the institutions that employ and fund them to resist third party challenges after the fact, but also should outline the precautions, methods and dedicated resources that can and should be put in place ahead of time to ensure that resistance is most effective. In particular, in cases where confidentiality is essential for the acquisition of valid data, and the potential adverse impact of disclosure on the participant is significant, SSHWC has identified the following responsibilities for researchers, Research Ethics Boards, university administrations, and the granting agencies:

### **7.1.1 Researchers**

- should design their research in such a manner that it either (a) makes the identification of individual respondents impossible by gathering data anonymously or anonymizing it at the earliest opportunity; or (b) if participants remain identifiable, anticipates the Wigmore criteria;<sup>20</sup> and
- should inform institutional authorities, including their REB, as early as possible if they are identified as "persons of interest" or are the subject of legal action (e.g., subpoena) regarding research

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subpoenas in the U.S. has been grand juries, which do not exist in Canada, and hence have been omitted, although Canadians doing research in the U.S. should recognize them as a prospective threat.

<sup>20</sup> The onus is on the researcher to demonstrate how they meet the criteria. In practice, there are two main precautions researchers can take. Criterion 1 requires that there be an "expectation of confidentiality." Accordingly, researchers must be prepared to show evidence that the expectation was indeed made clear in their research. Toward this end, researchers are encouraged to have open and honest discussion with research participants about their confidentiality concerns, and to keep an anonymized record of their confidentiality agreement (e.g., as part of an anonymized interview transcript). Researchers who would in any way limit their pledge of confidentiality should ensure any agreement does not constitute a waiver of privilege. Criterion 2 requires that confidentiality be essential to the relationship. Although this is generally true of the researcher-participant relationship, researchers should again endeavour to establish that that is true *in their particular case*. A general discussion of that sort should be included in proposals to the REB so that it is a part of the documentary record, and anonymized records of any discussions with participants in that regard should be retained. See Jackson and MacCrimmon (1999) and Palys and Lowman (2000) for a more extensive discussion of ways researchers can effectively anticipate the Wigmore criteria in their research procedures.

confidentiality so that their institution of employment and kindred institutions and associations can be of assistance in providing the best possible protection to them and research participants.<sup>21</sup>

### **7.1.2 Research Ethics Boards**

- should expect proposals to incorporate security and design features that reflect the sensitivity of information to be gathered and the degree of harm that would accrue to research participants if disclosure were to occur; this would include an anticipation of the Wigmore criteria when confidentiality is essential and the prospective harm of disclosure to research participants is significant; and
- should avoid requiring the creation of identifying paper records (such as signed consent statements) when the existence of such records may compromise research participant confidentiality, unless the research participant specifically requests a copy, in which case their request should be honoured.

### **7.1.3 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 because defending their interests is a defence of academic freedom, the research enterprise and their own future viability;<sup>22</sup>
- should develop institutional policies that direct all university-affiliated researchers to bring the matter quickly to institutional attention, and direct them to a particular individual who can authorize obtaining preliminary legal advice; and
- because institutional interests may in some ways conflict with the interests of researchers and research participants, should ensure any legal representation of researchers and participants is at arm's length from legal representatives of the administration of the institution.

### **7.1.4 The Granting Agencies**

- 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.

### **7.1.5 Disciplinary and Professional Associations**

- should continue articulating disciplinary standards regarding confidentiality, filing *amicus curiae* briefs and serving as expert witnesses in court on behalf of researchers who assert privilege when third parties have sought identifiable research information, and promoting the development of statute-

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<sup>21</sup> When a subpoena arrives, the time to respond can be brief, so it is prudent to have policies in place that affirm the moral obligation to resist and specify, at least, who the researcher should approach for authorization for preliminary legal advice. See Michael Traynor's article entitled "Countering the Excessive Subpoena for Scholarly Research" in Cecil and Wetherington (1996). [The article is available online at [http://www.law.duke.edu/shell/cite.pl?59+Law+&+Contemp.+Probs.+119+\(Summer+1996\)](http://www.law.duke.edu/shell/cite.pl?59+Law+&+Contemp.+Probs.+119+(Summer+1996)) ].

<sup>22</sup> This includes ensuring that the resources are in place for an effective defence. For example, the Canadian Association of University Teachers (CAUT) has created an "academic freedom" fund with a target principal of \$1,000,000 that could conceivably be used to assist such an effort. Kwantlen University College in British Columbia also specifically set aside funds for legal challenges to confidentiality that were triggered when a Vancouver Island Crown Prosecutor subpoenaed a Kwantlen researcher who was observing, as part of his research, the trial of a woman charged with counseling suicide.

based privileges commensurate with researchers' ethical obligations to protect research participant privacy and confidentiality.

- 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.

Court decisions regarding claims of privilege make clear that the courts expect people who claim privilege to behave in a manner that is consistent with the seriousness of responsibility that goes with being in a privileged relation and its commensurate duty of confidentiality. Accordingly, SSHWC asks the research community's to consider whether the TCPS should make explicit the sets of obligations listed above. Our interim proposal is that it should. If the experience of researchers in Canada and the United States over the last three decades is any indication, challenges likely will arise infrequently, but when they do, there will be much at stake and the courts will scrutinize every aspect of the researcher's, REB's and institution's behaviour, as well as the TCPS and its provisions. Researchers' track record with the courts in both Canada and the United States is a good one; in most cases the courts have recognized the importance of research confidentiality to academic freedom and of academic freedom to effective inquiry, and often have gone out of their way to protect research participants.<sup>23</sup> This means there is good reason to be optimistic about the outcomes for research participants if a claim of privilege ends up in court, but REBs and researchers must do their part to ensure the court has "good facts" on which to base its decision.

## **7.2 The Researcher's Dilemma**

The main difficulty with the law in Canada as it pertains to research confidentiality is that, for everyone other than Statistics Canada researchers and their participants, it is a law created after the fact, while researchers must make their pledges to research participants ahead of time. We hope the courts will appreciate and affirm our ethical duties in the completion of our academic mission, but in the current state of law, even if we do all due diligence with respect to meeting the Wigmore criteria, there are no guarantees. This means that, in theory at least, law and ethics "may lead to different conclusions" (p.i-8).

This prospective divergence of ethics and law places researchers in the position where they must make a choice at the outset as to whether they will prioritize ethics or law at the rare last instant when and if the two part company. The three granting councils have made clear that researchers do indeed have the right to make such a choice, and have outlined some of the responsibilities that flow from those choices.<sup>24</sup> Whatever their choice, researchers and REBs are obliged to act in a way that minimizes harm for the participant and maintains the integrity of the research process.

### **7.2.1 An "ethics-first" approach**

Those researchers who choose an "ethics-first" strategy should understand what they are getting themselves into, and the possible repercussions that may arise for them, but should also feel confident that the institutions that employ them will respect their decision and do everything possible to assist their legal defence. In the worst case, researchers who defy a court order for disclosure can be fined and/or incarcerated for contempt of court. We are aware of two researchers in the United States who have been

<sup>23</sup> For a compendium of cases, see Cecil and Wetherington (1996), Israel (2004) and Lowman and Palys (2001).

<sup>24</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>



jailed for their ethical commitment to maintain research confidentiality in the face of a court order for disclosure:<sup>25</sup> Harvard political scientist Samuel Popkin was jailed for 8 days in 1972 for his refusal to identify sources behind the *Pentagon Papers*; and Washington State University sociology graduate student Richard Scarce was jailed for 159 days in 1995 for his refusal to divulge the content of research conversations he had with an animal rights activist accused of extensive vandalism of the university's animal laboratory facilities.

SSHWC accepts this defiance as an ethical approach that is an unfortunate by-product of the current state of Canadian law, and enjoins research institutions to ensure that in the unlikely event this worst case scenario were to occur, researchers are not penalized for their ethical observance. Any fines should be paid by the institution, for example, and researchers' employment status and conditions of employment should not be affected by any incarceration; student researchers should experience no loss of status and appropriate consideration should be shown regarding the completion of course requirements.

### **7.2.2 A "law-first" approach**

The "law-first" approach begins with the researcher acknowledging that, while s/he will live up to the expectation articulated in the TCPS to do everything possible within the law to resist disclosure of research confidences, if, in the last instant a court of last resort were to order disclosure, the researcher would comply with that order.

While the "ethics-first" approach is reasonably straightforward in its requirements, the "law-first" strategy is less so because complying with an order for disclosure would appear to violate the TCPS injunction to maintain research confidentiality unless the research participant gives his or her "free and informed consent" (p.3-1). And as the TCPS goes on to explain, "Breaches of confidentiality may cause harm: to the trust relationship between the researcher and the research subject; to other individuals or groups; and/or to the reputation of the research community" (p.3-1). If the effect of a disclosure were to cause the research participant harm then it would be a violation of the ethical injunction to ensure that research participants are not harmed by their participation in our research, and of the responsibility all researchers and research institutions share to maintain the integrity of the research enterprise. It thus behoves us to consider what an ethical "law-first" strategy that respects law while incurring no harm for research participants would look like.

## **7.3 Avoiding a Research Equivalent of *Caveat Emptor***

Generally speaking, "law-first" approaches emphasize that there are theoretical legal limits to confidentiality and that any researcher who would follow legal orders for disclosure should warn prospective research participants of that possibility. While the "law-first" approach is clearly an ethical one, the primary danger that the TCPS and institutions should safeguard against is any devolution of this approach into a research equivalent of *caveat emptor*. This would occur in its most obvious and extreme form when a researcher dismisses strict confidentiality as unattainable; replaces it with a complete reliance on informed consent; and asserts that violations of confidentiality are acceptable as long as researchers warn participants ahead of time this might occur. While this approach might be justified by interpreting the TCPS assertion that "the researcher has a duty not to share the information with others without the subject's free and informed consent" (p.3-1) as legitimizing disclosure, researchers cannot pick and choose the ethical principles to which they will adhere, and an exclusive emphasis on informed consent is problematic to the extent it excludes or ignores other equally important principles. The

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<sup>25</sup> No Canadian researcher, as far as we know, has ever been jailed under similar circumstances.

dismissal of confidentiality in favour of informed consent as reflected in the *caveat emptor* extreme is ethically unacceptable for four main reasons:

- The TCPS recognizes that “Breaches of confidentiality may cause harm: to the trust relationship between the researcher and the research subject; to other individuals or groups; and/or to the reputation of the research community” (p.3-1). The *caveat emptor* approach allows that harm to occur, thereby failing to meet the TCPS principle that information that could cause harm must be kept confidential (TCPS, p.3-1).
- The *caveat emptor* approach appears to download responsibility for the management of information to research participants. Most research participants are likely to be unaware of how legal principles and procedures interact with research confidentiality; investigators cannot abdicate the ethical responsibility and fiduciary obligation they have for managing sensitive information and protecting participant interests.
- Depending on how a warning about the possibility of disclosure is constructed, it may constitute a “waiver of privilege.” Investigators cannot make the waiving of rights, including the right to claim privilege, a condition of participation. Doing so is a violation of the TCPS principle that researchers as a minimal standard are “honour-bound” to protect research participants “to the extent possible within the law.” (TCPS, p.3-2)
- Continuing to acquire information that benefits the researcher (through publications, fame, merit increases and so on) and society (in the form of greater understanding) while divesting oneself of responsibility for ensuring no harm comes to the participant is exploitative, and violates what the TCPS identifies as a fundamental moral imperative: “Part of our core moral objection would concern using another human solely as a means toward even legitimate ends” (p.i-4).

In view of these concerns, SSHWC suggests an ethical “law first” approach that avoids the research equivalent of “*caveat emptor*” involves the following elements:

### **7.3.1 Informing Participants**

Researchers who take a “law-first” approach and limit confidentiality by law should inform participants of those limitations as part of the consent process whenever identifiable information they expect to gather could cause harm to the participant if disclosed. At the same time, they should assure prospective participants that they will nonetheless do “everything possible” to protect research confidences, and that they and the institutions that employ and fund them are obliged under the TCPS to live up to that commitment (TCPS, p.3-2).

### **7.3.2 Avoiding Waivers of Privilege**

Researchers cannot require prospective participants to waive any legal rights – including the right to claim privilege – as a condition of participating in their research. In particular, there is a concern that any limitation of confidentiality by law might constitute such a “waiver of privilege.”<sup>26</sup> Anything that would

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<sup>26</sup> Just what might constitute a “waiver of privilege” has yet to be determined. In *Atlantic Sugar v United States* [1980. 85 Cust. Ct. 128], corporate respondents to an International Trade Commission questionnaire were told that the information they provided would not be disclosed “except as required by law.” A U.S. Customs Court treated this as a waiver of privilege to justify its order of disclosure of research information from researchers. The *Atlantic Sugar* case is in no way binding on Canadian courts, but offers a cautionary tale of as to how researchers can inadvertently undermine the rights of participants.

The most relevant Canadian case on the matter of waivers of privilege is the Canadian Supreme Court case of *AM v Ryan* ([1997] 1 S.C.R. 157). When lawyers for the plaintiff argued that the fact AM’s psychiatrist discussed

undermine the researcher's ability to assert privilege on behalf of the participant would be a violation of the TCPS injunction that, as a minimum standard, researchers are honour-bound to protect research confidences "to the extent possible within the law" (p.3-2).

### **7.3.3 Ensuring No Harm Can Result**

The *caveat emptor* approach to ethics is unacceptable in part because it involves researchers gathering information and the rewards their research accrues (publication, promotion, royalties, fame), and society benefiting from the knowledge created, at the expense of research participants. This is exploitative and a violation of what the TCPS describes as a moral imperative: "Part of our core moral objection would concern using another human solely as a means toward even legitimate ends" (p.i-4). Accordingly, we suggest researchers should consider either not gathering any information that could harm the participant if it were to be disclosed that they are not prepared to defend, or if they do gather it, to not record it in any identifiable form that can be accessed by a third party.<sup>27</sup>

## **8. Unanticipated Heinous Discovery**

Even though there may be no legal requirement to report it, researchers may unexpectedly discover information regarding prospective harm to an innocent third party that is so heinous they feel ethically compelled to violate the pledge of confidentiality they had offered in good faith. This has been referred to in the literature as the problem of "unanticipated heinous discovery."

Although a very rare situation, we can imagine few situations as heart-wrenching for the ethical researcher than one in which a researcher is faced with the prospect of violating a pledge that was made in good faith to a participant one has an ethical obligation to protect. Certainly the matter is more complex than a simple "duty to report." A preliminary analysis is offered below, along with our encouragement to readers of this document to bring alternative perspectives or approaches to this issue to our attention.

### **8.1 The Truth is Rarely Simple**

Although policies that speak of a "duty to report" make the decision seem relatively straightforward – one serendipitously comes across the information that some heinous event will occur unless the researcher intervenes and the researcher feels ethically compelled to do so – life's choices are rarely so clearly defined:

- (a) What happens when the source of the information is not the party who ostensibly will carry out the heinous deed? Is gossip and hearsay a reasonable basis on which to trigger a violation?

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the possibility of court-ordered disclosure with her constituted a waiver of privilege by failing Wigmore criterion 1 – no expectation of confidentiality – the Supreme Court disagreed. They pointed instead to the psychiatrist's promise – that she would do "everything possible" to protect her client's confidences – and the consistency of her behaviour with respect to that promise – resistance to disclosure and assertion of privilege at every turn – as evidence consistent with the idea that an expectation of confidentiality still prevailed.

<sup>27</sup> This practice is suggested on the basis of the Supreme Court of Canada's ruling in *A.M. v Ryan* [1997]. In that case, a psychiatrist was forthright in informing her client that, although she would resist any efforts by third parties to force disclosure records of therapy, ultimately she would disclose written records of the therapy if ordered to by the Supreme Court. However, she safeguarded her client by ensuring that matters that could be injurious to her client were never recorded and thus were unavailable for disclosure. [For a copy of the full decision, see <http://www.lexum.umontreal.ca/csc-scc/en/pub/1997/vol1/index.html> and search for "Ryan."]

- (b) How is one to distinguish whether the information is real or whether the respondent is simply testing the researcher and/or pulling his/her leg?
- (c) Who is an appropriate person to judge whether the threat is real?

All of these concerns speak to the issue of competent judgment, and a recent U.S. court case offers a cautionary tale. The incident occurred in Georgia, and arose when a psychologist doing interviews with members of a municipal police force listened as one officer described, in confidence, his fantasies of killing the police chief and other members of the force. The psychologist took the description seriously, informed the chief of the alleged danger, and initiated a chain of events that ended with the termination of the interviewed officer's career in policing. The officer later sued the psychologist for defamation and negligence and won an award of \$287,000, claiming that the psychologist over-reacted to stories that were nothing more than fantasy.<sup>28</sup>

Although this case has no precedent value in Canada, it is relevant for other reasons. In particular, it is interesting that this error of judgment occurred even though clinical psychologists are people who are trained to make determinations about mental states and distinguish between the real and fantasy lives of their clients. What ethical issues arise in the research context when the researcher who unexpectedly hears what seems to be a heinous revelation is an anthropologist, political scientist, or kinesiologist? Codes of professional ethics admonish us not to make decisions about matters for which we have no professional competence. Does that standard apply here as well? Or is a lay standard of "reasonable belief" sufficient when the integrity of the research enterprise and, perhaps, the well-being of an innocent third party, hang in the balance?

## 8.2 What Prospective Harm Might Make Voluntary Disclosure Permissible?

Another issue to be considered is the magnitude of harm that must exist in order for an intervention to be triggered, i.e., what minimal threshold must be exceeded before the violation of a pledge of confidentiality made in good conscience is permissible?

This issue was addressed in a recent Canadian Supreme Court case referred to as *Smith v Jones*.<sup>29</sup> Although the case dealt with an unanticipated heinous discovery situation in relation to solicitor-client privilege, the court's decision is relevant to the research domain as well because, as the Justices explained,

[Solicitor-client-privilege] is the highest privilege recognized by the courts. By necessary implication, if a public safety exception applies to solicitor-client privilege, it applies to all classifications of privileges and duties of confidentiality.

Upon hearing an application to have solicitor-client privilege (which is a "class" privilege that has been recognized in common law) set aside, the Justices articulated three criteria that must be met before a violation of a pledge of confidentiality made in good faith might be permissible: the prospective harm to a third party (1) must involve the prospect of serious injury or death; (2) must be imminent; and (3) must involve a clearly identifiable target. Even then, the Justices stopped short of creating any "duty to report"

<sup>28</sup> *Garner v. Stone* (1999). Georgia State Court (DeKalb County). No. 97A-30250-1. Reported in T. Renaud (2000). "Jury Awards \$287,000 for Psychologist Telling of Client's Lethal Fantasies." *Fulton County Daily Report*, January 5.

<sup>29</sup> *Smith v Jones* [1999] 1 S.C.R. 455. A copy of the full decision is available online at <http://www.lexum.umontreal.ca/csc-scc/en/pub/1999/vol1/index.html>. Do a search there for "Smith."

under these circumstances, stating instead that while nothing less than that would justify violating a duty of confidentiality, the presence of all three criteria should initiate a detailed case-by-case consideration of its appropriateness in a manner they outlined in greater detail in their decision.

### **8.3 Enduring Obligations to the Participant**

Even if the criteria are met and the decision is made to violate the confidence in order to protect the third party, the matter is not so simple as merely “calling the police” and violating the confidence. Rather, the Justices in *Smith v Jones* re-affirmed the ongoing obligation lawyers and those who came under their privilege<sup>30</sup> have to their clients, part of which is to ensure that they do not undermine their client’s right to a fair trial, and we take the obligation to researchers to be the same. This implies that any violation of confidence has to be the absolute minimum violation necessary to prevent the harm from occurring. And indeed, the Justices affirmed that “preventing the harm” is the objective here – which could be done by any of a variety of means including but not limited to calling the police – and not “jailing the accused.”

As appealing as it may be to ensure that Mr. Jones does not slip back into the community without treatment for his condition, completely lifting the privilege and allowing his confidential communications to his legal advisor to be used against him in the most detrimental ways will not promote public safety, only silence. For this doubtful gain, the Court will have imposed a veil of secrecy between criminal accused and their counsel which the solicitor-client privilege was developed to prevent. Sanctioning a breach of privilege too hastily erodes the workings of the system of law in exchange for an illusory gain in public safety.

### **8.4 Should a “Heinous Discovery” Warning be Part of Informed Consent?**

A final issue concerns whether, in the interests of informed consent, prospective participants should be informed if an unanticipated heinous discovery would lead the researcher to violate a pledge of confidentiality. Although there might be some instances in which researchers might consider it appropriate, SSHWC advises in general against it for three main reasons.

First, researchers have no obligations to inform prospective participants about issues that are outside the expected bounds of the research, and “unanticipated heinous discovery” is, by definition, an unanticipated discovery. This makes a warning difficult to construct, even if desired, for two main reasons: (1) it is likely impossible to outline the range of unique circumstances that might lead the researcher to violate a confidence; and (2) research participants might well find it bizarre and/or offensive to be warned about possibilities that have nothing to do with the area of inquiry.

We also note the paradox that any requirement to limit confidentiality to account for “unanticipated heinous discovery” creates. The main reason for considering the notion of “unanticipated heinous discovery” in the first place is presumably because of recognition of the concern we would have for some innocent third party whose victimization we serendipitously discover is imminent. But if we give a warning that indicates we would intervene if respondents were to tell about some prospective heinous action, it becomes less likely the respondent who is planning such an action will tell us of his/her intentions, with the paradoxical result that our warning makes it more likely the prospective victim will indeed be harmed.

And finally, unanticipated heinous discovery is an incredibly rare event. In that context, giving warnings because of the remote possibility of some heinous revelation falling in our laps is the wrong emphasis and

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<sup>30</sup> The action in *Smith v Jones* was brought forward by a psychiatrist who was asked to examine the accused (who was planning on entering a guilty plea) to prepare a report that would speak to sentence. It was treated as an instance of lawyer-client privilege because it was part of the preparation of defense.

contrary to the fiduciary duty we have to protect participant interests. Information is far better given in the opposite direction – where researchers consider, and research participants hear, how important confidentiality is to the research enterprise, and the considerable lengths we will go to defend it.

## 8.5 A Draft Policy

On the basis of the above considerations, we suggest the following guidelines for the research community’s consideration as guidelines for “unanticipated heinous discovery.”<sup>31</sup>

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### Draft Guidelines for “Unanticipated Heinous Discovery”

#### Preamble

The *Tri-Council Policy Statement (TCPS p. i-5)* holds that privacy and confidentiality are core research ethics principles. However, the *TCPS* recognizes that research ethics principles are not absolute; they interact with various other ethical and legal obligations.

With regard to confidentiality, it is conceivable that, on very rare occasions, a researcher might violate a guarantee of confidentiality in order to satisfy what they believe to be a higher ethical obligation, such as saving someone’s life. When such a possibility is outside the terms of reference for the research, this is a problem of “unanticipated heinous discovery.” What should a researcher do if, out of the blue, a research participant says that they intend to harm a third party? What degree of harm justifies violating confidentiality? What ethical guidelines should researchers follow in such cases? Are there any legal guidelines that need to be taken into consideration?

When it comes to law, there are no North American cases dealing with the legal obligations of researchers confronting heinous discovery. However, there is some case law in Canada and the U.S. pertaining to doctors and lawyers – both of whom are ethically and legally bound to maintain confidential relationships with their clients – when a patient or client divulges that they intend to murder someone. In the U.S. at least one patient made good such a threat.

In Canada the most significant case pertaining to how doctors and lawyers should deal with unanticipated heinous discovery is *Smith v. Jones* ([1999] 1 S.C.R. 455) where the Supreme Court of Canada describes three criteria comprising the “public safety exception” to solicitor-client privilege. These unanticipated heinous discovery guidelines for researchers are adapted from this case.

#### The Public Safety Exception as a Matter of Research Policy

Three factors should be taken into consideration when deciding whether a higher ethical principle – preventing a harm – outweighs a researcher’s obligation to maintain confidentiality.

- 1) *Seriousness*: Is there a risk of serious bodily harm or death?
- 2) *Imminence*: Is the danger imminent?

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<sup>31</sup> These guidelines are adapted from those formulated by the School of Criminology at Simon Fraser University upon request of the President of Simon Fraser University. They were ratified unanimously at a Faculty Meeting of the School, and are now being considered for university-wide adoption.

3) *Clarity*: Is the risk directed to a clearly identifiable person or group of persons?

These three criteria set the bar for the nature and extent of threat that must exist before confidentiality can be violated. If the harm does not reach this threshold – i.e., it is not clear, serious and imminent - then confidentiality should be maintained. If it exceeds this threshold, it should be decided on a case-by-case basis whether a violation of confidentiality is warranted.

If a violation of confidentiality is warranted, the researcher still has a duty to protect the research participant as much as possible by limiting the extent to which confidential information is made available. Any violation should only be to the extent required to nullify the threat being posed. If time allows, researchers should seek advice from trusted colleagues about the best way to respond to the particular threat.

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We encourage researchers, academic units, REBs and research administrators to contact SSHWC if they have comments on these guidelines and/or would like to propose alternatives for consideration.

## 9. Mandatory Reporting Laws

### 9.1 Diverse Approaches to Mandatory Reporting

The TCPS refers to mandatory reporting laws by noting that, “The values underlying the respect and protection of privacy and confidentiality are not absolute,” and that “Compelling and specifically identified public interests ... may justify infringement of privacy and confidentiality.” Mandatory reporting laws reflect such an interest, although their application to the research context is controversial. Some researchers view mandatory reporting laws as appropriate social policy and may even have campaigned for their creation. Others believe the lack of any exemption for research in these laws impedes the ability of researchers to gather valid information about some of society’s most pressing and tragically consequential social issues. The TCPS should acknowledge both these perspectives as reasonable and ethical while discussing the responsibilities that accrue to each.

The existence of mandatory reporting laws creates for both groups of researchers a conflict of interests they must resolve ahead of time when it is reasonably plausible they will hear about reportable behaviour in their research. The researcher who would willingly report behaviour that is subject to mandatory reporting provisions has interests at odds with the participant they have a duty to protect; the researcher who disagrees with mandatory reporting provisions must nonetheless deal with their existence. The general principle that applies to both is that they must attempt to resolve the conflict before undertaking the research. The ways this is done may vary according to the disciplinary standards and professional affiliation of the researchers, and we invite researchers who have had to deal with this dilemma to inform us of their experiences and its impact on their research.<sup>32</sup>

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<sup>32</sup> Although the reference here is to mandatory reporting laws, similar issues arise in relation to organization-specific codes and policies where the code or policy places the researcher in a conflict of interest. Such conflicts must be resolved before the research begins. This is reflected in the current TCPS, which states, “Article 2.4(e) reminds researchers of relevant ethical duties that govern potential or actual conflicts of interest, as they relate to the free and informed consent of subjects. To preserve and not abuse the trust on which many professional relations reside, researchers should separate their role as researcher from their roles as therapists, caregivers, teachers, advisors, consultants, supervisors, students or employers and the like. If a researcher is acting in dual roles, this fact must always be disclosed to the subject. Researchers should disassociate their role as researcher from other roles, in the recruitment process and throughout the project.”

## 9.2 Direct Questioning of Reportable Behaviour

SSHWC cannot understand how any researcher could justify asking participants directly and gathering identifiable data about behaviour they would knowingly report. Gathering such information without informed consent would be deceptive and would undermine the integrity of the research enterprise by equating research with a policing function. Although stated in the TCPS in relation to international research, SSHWC believes it is equally true for research in Canada that it is, "... unethical for researchers to engage in covert activities for intelligence, police or military purposes under the guise of university research. REBs must disallow any such research." (TCPS, p.1-12). A similar injunction appears on p.2-4: "Researchers should avoid being put in a position of becoming informants for authorities or leaders of organizations."

Gathering reportable information *with* informed consent would seem exploitative and, in any event, any identifiable data surely would be of questionable validity. The only acceptable way that we can think of for the reporting researcher to gather such information would be for him or her to gather the data under conditions of complete anonymity, so that neither the researcher nor anyone else could ever connect any reportable behaviour to any particular individual.

## 9.3 Where Touching on Mandatory Reporting Laws is Plausible

In a second situation we can envision circumstances in which researchers might wish to ask questions in the general area of a reportable behaviour – interviewing parents about their child-rearing practices, for example – where it is foreseeable that some respondents might describe practices that would come under mandatory reporting provisions. SSHWC believes it is important in such circumstances for participants to be made aware of both the mandatory reporting provisions and the researcher's interpretation of them. In British Columbia, for example, the mandatory reporting law regarding ongoing victims of child abuse requires persons to report when they have "reasonable grounds to believe that a child is in need of protection." The researcher should consider what sort of circumstances would lead them to believe that a child was "in need of protection," and what sorts of evidence would constitute "reasonable grounds" for that belief, and explain their view of those reporting triggers to prospective participants. Legal opinions regarding the more liberal and conservative interpretations of these terms would benefit both groups of researchers in ensuring that both made every effort to operate within the law while maintaining their ethical obligations to participants. We welcome researchers who have faced such situations to inform us of any other resolutions they believe are appropriate.

## 9.4 When Third Parties Are Affected

Matters become more complicated when it is a third party who would be affected by the mandatory reporting requirement, and not the participant, who in some instances might be the person the researcher believes s/he would be protecting. For example, a medical researcher interviewing patients about the treatment they have received might be told of events that constitute negligent or abusive treatment that s/he is obliged to report. Alternatively, a researcher who interviews adolescents about their relations with adults might conceivably hear about situations that lead them to believe the adolescent is in need of protection.

SSHWC has seen no informed legal analyses of these situations and suggest they would be useful. Is a one-sided view of adverse treatment sufficient to create "reasonable and probable cause" for believing a minor is "in need of protection"? If the participant is the one with the "reasonable and probable" belief is it appropriate for the researcher to inform them of their alternatives and leave reporting to them? How



should researchers deal with what is effectively “hearsay”? A balanced legal analysis of these ethical issues would be most welcome, as would any information that is available regarding participant perspectives in different contexts. In the interim, researchers treading into such areas are obliged to inform themselves of the legal issues that may affect them, the disciplinary standards associated with their research, and consider what their ethical resolution to those difficult dilemmas will be prior to engaging in the research. As a minimum, there should be a full and frank discussion with the participant of what the researcher believes his/her reporting requirements are, what sorts of incidents in the eyes of the researcher would trigger that reporting, and whether the researcher would heed, consider, or ignore the views of the participant in such an eventuality.

## **10. Affecting the Development of Law Through Ethical Approaches**

In addition to noting that law and ethics can “lead to different conclusions,” the TCPS also reminds us that, “[al]though ethical approaches cannot pre-empt the application of the law, they may well affect its future development” (p.i-8).

A literature now exists regarding the interaction of law and ethics when our ethical obligations to protect research confidentiality are challenged by third parties. It tells us that when third parties challenge research confidentiality, and researchers and their institutions resist through an assertion of privilege, the courts will inspect every aspect of their behaviour, and of their institutions’ behaviour, to determine whether the researcher and the research enterprise of which we are a part have acted in a manner that is consistent with the possession of privilege. It also tells us what the research community needs to do in order to produce good “case facts” that will maximize the likelihood of courts generating decisions and recognizing privilege in a way that is most beneficial to research participants, researchers, and the Canadian public. Much of that advice appears in this document.

Other areas remain far more ambiguous, however, and we can only encourage Canada’s research communities to contribute to those discussions regarding the impact and ethics of mandatory reporting laws, for example, as well as the creation of an interpretive guide that explains what those laws mean in the course of our everyday lives as researchers and professionals. Much also needs to be known about the role that privacy law and legislation might play in the protection of research confidentiality. We encourage the research community to assist SSHWC in the short term by sharing their observations and perspectives on these issues, and helping all of us in the long term by contributing to the literature that will influence development of law to better reflect ethical perspectives in future.

## **11. Selected Bibliography**

Cecil, J.S., and Wetherington, G.T. (eds.) (1996). Court-ordered disclosure of academic research: A clash of values of science and law. *Law and Contemporary Problems* (Special issue), 59(3).

This special issue of *Law and Contemporary Problems* arose from a colloquium on the topic following a spate of subpoenas in the U.S. that were not adequately covered by the statute-based protection of confidentiality certificates and privacy certificates that exist in the United States. The volume is a fundamental reference for those interested in the area. [Available online at <http://www.law.duke.edu/journals/lcp/lcptoc59dsummer1996.htm> ]

Israel, M. (2004). Strictly confidential? Integrity and the disclosure of criminological and socio-legal research. *British Journal of Criminology*, 44: 715-740.

An up-to-date international review of issues regarding the confidentiality of sensitive research information.

Jackson, M., Q.C., and MacCrimmon, M. (1999). *Research Confidentiality and Academic Privilege: A Legal Opinion*. [Online at <http://www.sfu.ca/~palys/JackMacOpinion.pdf> ]

A legal opinion commissioned by Simon Fraser University's Ethics Policy Revision Task Force regarding the notion of "academic privilege." A commentary on the opinion entitled *Research Confidentiality and Researcher-Subject Privilege: An Ethics-Based Opinion* is also available online at <http://www.sfu.ca/~palys/Privilege.html>

Palys, T.S., and Lowman, J. (2000). Ethical and legal strategies for protecting confidential research information. *Canadian Journal of Law and Society*, 15(1), 39-80.

An extended discussion of how researchers can incorporate anticipation of the Wigmore criteria into their research designs in the event that the confidentiality of their research data is ever challenged by a third party subpoena and their assertion of privilege is adjudicated by the court. [This article is available online by permission of the journal at <http://www.sfu.ca/~palys/Strategies-CJLS.pdf> ]

Traynor, M. (1996). Countering the excessive subpoena for scholarly research." In Cecil and Wetherington (1996). (see above).

Michael Traynor is a U.S. lawyer whose article outlines the preparatory, preventative, and reactive responses that are associated with the researcher and their institutions doing "everything possible" to protect research confidentiality. Although some of the advice is specific to the U.S. legal system, much of it is applicable to Canada. The article is online at [\[http://www.law.duke.edu/shell/cite.pl?59+Law+&+Contemp.+Probs.+119+\(Summer+1996\)\]](http://www.law.duke.edu/shell/cite.pl?59+Law+&+Contemp.+Probs.+119+(Summer+1996)).