

Consultation

Reconsidering Privacy and Confidentiality in the TCPS

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Interagency Advisory Panel on Research Ethics
Social Sciences and Humanities Research Ethics Special
Working Committee (SSHWC)



Government of
Canada

Gouvernement du
Canada

Canada

Secretariat on Research Ethics
350 Albert Street
Ottawa ON Canada
K1A 1H5
Fax: (613)996-7117
sshwc@pre.ethics.gc.ca
www.pre.ethics.gc.ca

Reconsidering Privacy and Confidentiality in the TCPS: A Discussion Paper

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

9 October 2005

Members

Dr. Mary Blackstone
Dr. Lisa Given
Dr. Joseph Lévy
Dr. Michelle McGinn
Dr. Patrick O'Neill
Dr. Ted Palys
Dr. Will van den Hoonaard (Chair)

Ex-Officio Members

Dr. Glenn Griener (NCEHR)
Dr. Deborah Poff (CFHSS)
Dr. Keren Rice (SSHRC)

Secretariat on Research Ethics

Ms Thérèse De Groot

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For consultation purposes, SSHWC can be reached at:

sshwc@pre.ethics.gc.ca

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9 October 2005

1
2 **1. The Purpose of this Discussion Paper**

3
4 This discussion paper reflects SSHWC's thinking to date about privacy and confidentiality issues
5 in the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS). It
6 contains preliminary discussions and some draft proposals that address privacy and
7 confidentiality issues not yet considered in the TCPS that were identified as matters of concern
8 during the consultations that culminated in SSHWC's earlier report entitled *Giving Voice to the*
9 *Spectrum* (2004).¹ It does not purport to identify or resolve all outstanding issues related to
10 privacy and confidentiality, but does speak to some of the more significant concerns raised by the
11 many qualitative and interpretive field-based researchers who participated most actively in our
12 consultations with Canada's Social Sciences and Humanities research communities, and whose
13 perspectives and approaches have yet to be fully recognized in the TCPS.

14
15 The objective of this discussion paper is not to put forth final policy recommendations but to offer
16 proposals and identify some options that have been brought forward to date. We do this in the
17 interest of promoting further discussion by the research community – wondering not only whether
18 we have adequately captured the diversity of views persons from the social sciences and
19 humanities would bring to the issues, but also how the principles we identify would play out in
20 other disciplines and perspectives – anticipating this will lead to the identification of other
21 alternatives that will need to be considered during the dialogue. SSHWC's development and
22 recommendation of specific policy options and proposals for changes to the TCPS will arise from
23 that dialogue, and will be the subject of future reports and consultations.

24
25 We encourage comments and reactions to this report from researchers, research ethics
26 administrators, Research Ethics Board (REB) members and other interested parties from the
27 social sciences and humanities and other disciplines that we can consider prior to drafting

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

28 recommendations for consideration by the Interagency Advisory Panel on Research Ethics (PRE)
29 regarding privacy and confidentiality issues.²
30

31 2. Respect for Privacy and Confidentiality

32

33 2.1 Privacy and Confidentiality as “Guiding Principles” of Ethics

34

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

37

38 **Respect for Privacy and Confidentiality:** Respect for human dignity also implies the principles
39 of respect for privacy and confidentiality. In many cultures, privacy and confidentiality are
40 considered fundamental to human dignity. Thus, standards of privacy and confidentiality protect
41 the access, control and dissemination of personal information. In doing so, such standards help to
42 protect mental or psychological integrity. They are thus consonant with values underlying privacy,
43 confidentiality and anonymity respected. (p. i.5)
44

45

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

50

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

55

56 2.2 Privacy from Research(ers)

57

58 Notwithstanding the social mandate that university researchers have to understand all aspects of
59 society, the ethical and legal claim of people to privacy implies that researchers cannot gather
60 whatever information they wish about whomever they wish whenever and wherever they wish. In
61 relation to that invasiveness, the TCPS emphasizes the desirability of informed consent wherever
62 possible, so that prospective participants can choose whether to let researchers into their lives on
63 terms that are negotiated, or at least understood. That is particularly so when the data are gathered
64 and maintained so as to be identifiable as to their source [hereafter referred to as “identifiable
65 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

² Comments can be sent to SSHWC at sshwc@pre.ethics.gc.ca .

³ 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 these 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.

66 key factor that makes any research, and particularly research without explicit consent, ethical. As
67 explained in the TCPS,

68
69 ...[W]ithout access to personal information, it would be difficult, if not impossible, to conduct
70 important societal research in such fields as epidemiology, history, genetics and politics, which
71 has led to major advances in knowledge and to an improved quality of life. The public interest
72 thus may justify allowing researchers access to personal information, both to advance knowledge
73 and to achieve social goals such as designing adequate public health programmes.

74
75 Historically, the benefits of the confidential research use of personal data have been substantial.
76 Two of many such examples are: the identification of the relationship between tobacco and lung
77 cancer; and the use of employment or educational records to identify the benefits or harms of
78 various social factors. In the last two decades, larger data bases and newer techniques have
79 improved the capacity of researchers to evaluate the delivery of services and the outcomes of
80 many procedures and products. These studies have contributed to more responsive and efficient
81 service delivery in areas such as health, education, safety and the environment.

82
83 Ethics review is thus an important process for addressing this conflict of societal values. The REB
84 plays an important role in balancing the need for research against infringements of privacy and
85 minimizing any necessary invasions of privacy. (pp. 3.1-3.2)

86
87 When informed consent is sought, and the research ethics board (REB) has approved the
88 representations on which that consent will be based, prospective participants who are competent
89 can decide for themselves whether they are prepared to allow whatever infringement of their
90 privacy the proposed research involves. When it is not, the REB, guided by a subject-centered
91 perspective, and with respect for the academic freedom of researchers, will undertake to consider
92 whether the approach proposed by the researcher is consistent with disciplinary standards and the
93 Policy Statement.

95 2.3 Protecting Privacy through Confidentiality

96
97 In the event the prospective participant decides to take part in the research, or the REB provides
98 clearance even though the prospective participant has not been asked, the TCPS makes clear that
99 a duty befalls the researcher to protect rights to privacy by ensuring any identifiable information
100 remains strictly confidential unless directed otherwise by a research participant:

101
102 Information that is disclosed in the context of a professional or research relationship must be held
103 confidential. Thus, when a research subject confides personal information to a researcher, the
104 researcher has a duty not to share the information with others without the subject's free and
105 informed consent. Breaches of confidentiality may cause harm: to the trust relationship between
106 the researcher and the research subject; to other individuals or groups; and/or to the reputation of
107 the research community. Confidentiality applies to information obtained directly from subjects or
108 from other researchers or organizations that have a legal obligation to maintain personal records
109 confidential. In this regard, a subject-centred perspective on the nature of the research, its aims and
110 its potential to invade sensitive interests may help researchers better to design and conduct
111 research. A matter that is public in the researcher's culture may be private in a prospective
112 subject's culture, for example.

113
114 There is a widespread agreement about the rights of prospective subjects to privacy and the
115 corresponding duties of researchers to treat private information in a respectful and confidential
116 manner. Indeed, the respect for privacy in research is an internationally recognized norm and
117 ethical standard. It has been enshrined in Canadian law as a constitutional right and protected in

118 both federal and provincial statutes. Model voluntary codes have also been adopted to govern
119 access to, and the protection of, personal information. (CIHR *et al* 1998, p.3-1)
120
121

122 3. Articulating Privacy and Confidentiality Issues

123
124 On matters described above, SSHWC is in accord with the current section of the TCPS regarding
125 Privacy and Confidentiality. However, three priority areas were flagged for further development
126 during the consultations reported in *Giving Voice to the Spectrum* (SSHWC, 2004) and are the
127 foci of this discussion paper:
128

129 3.1 Understanding the Implications of a “Subject–Centered 130 Perspective” to Privacy and Confidentiality Issues

131
132 In Section 4 of the discussion paper, we urge further development related to a subject-centered
133 perspective, offer some interim proposals, and encourage researchers and those who participate in
134 their research to contribute to this important area.
135

136 3.2 Articulating a Range of Approaches to Confidentiality 137 Issues

138
139 SSHWC suggests the TCPS should include a clearer articulation of the range of issues that
140 researchers and REBs should consider when determining what approach to confidentiality is most
141 appropriate in their particular context. A preliminary description of the range of possibilities is
142 included in Section 5 below.
143

144 3.3 Considering the Relationship Between Ethics and Law

145
146 Although we always hope and should aspire to be both ethical and legal, the TCPS recognizes
147 that occasions may arise when law and ethics “may lead to different conclusions” (p. i-8).
148

149 Section 6 outlines ways in which research confidentiality and law appear to coincide through
150 legal mechanisms that do or may protect research participants, as well as areas in which the ethics
151 and law of research confidentiality may come into conflict.
152

153 Sections 7 through 9 consider areas of prospective ethics-law conflict in greater detail, and
154 outline a range of alternatives and obligations that researchers can consider when designing their
155 research, and that REBs should consider when scrutinizing their proposals.
156

157
158
159

160 4. A “Subject–Centered Perspective” on Privacy 161 and Confidentiality

162 Although the TCPS requires researchers and REBs to adopt a “subject-centered perspective”
163 when generating and evaluating research proposals, the 1998 TCPS contains no guidelines for
164 researchers and/or REBs as to what we know about those perspectives, how they might be
165 relevant across different methods and approaches, and what ethics issues arise from applying that
166 principle across diverse areas of research. Despite its centrality to the research design and ethics
167 review process, there is little empirical evidence to date on this topic; the literature begs for
168 further development.
169
170

171 4.1 SSHWC Research Initiative

172
173 Toward that end, SSHWC is undertaking exploratory research regarding participants’
174 perspectives on confidentiality issues through a “Participants’ Perspectives” sub-group, and will
175 incorporate relevant findings into future working reports and recommendations. SSHWC
176 encourages other researchers to consider these issues in the context of their own research
177 domains, and we ask any researchers reading this discussion paper to share with us their
178 knowledge regarding the perspectives of participant populations with whom they work – whether
179 from their own direct discussions and observations or through literature of which they are aware –
180 particularly with respect to their expectations regarding privacy and confidentiality, and/or to
181 encourage participants to contact us directly.⁴
182

183 4.2 Some Interim Principles

184
185 Given the dearth of literature related to a subject-centered perspective, understanding participant
186 perspectives regarding confidentiality and considering their implications for ethics review will
187 not occur overnight. In the interim, we offer the following principles for researchers and REBs to
188 consider, and would appreciate the research community’s comments on their ethical
189 appropriateness and feasibility:
190

- 191 i. As a general principle, the greater the social distance between the participant group and
192 the researcher(s), the greater the effort that should be expended to solicit information
193 regarding participant perspectives on confidentiality provisions that would be
194 meaningful and appropriate to the participants in the proposed research context.
195
- 196 ii. As a general principle, the less the experience of the most senior researcher with the
197 participant group, the greater the effort that should be expended to solicit participant
198 perspectives regarding confidentiality provisions that would be meaningful and
199 appropriate to the participants in the proposed research context.

⁴ 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 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.

200 iii. When REBs do not have members who have had direct experience with the proposed
201 participant group, they should seek out and give significant weight to the
202 understandings of researchers who have that experience, including, if warranted by
203 his/her personal experience, the researcher making the application.⁵
204
205

206 **5. Approaches to Confidentiality**

207
208 One implication of incorporating a “subject-centered perspective” in relation to privacy and
209 confidentiality issues is the need to consider the range of relations and circumstances in which
210 they arise. While ensuring the provision of confidentiality with respect to the source of any
211 information gathered is the appropriate default assumption failing any agreement to the contrary –
212 both because confidentiality is a core ethical principle and because in most cases any waiving of
213 confidentiality can only be done by the participant – situational parameters and the need to
214 consider subject-centered perspectives may lead to other resolutions regarding the provision of
215 confidentiality. Researchers should identify in their proposals which option applies to their
216 research.

217
218 Researchers and research administrators who have other examples and approaches to suggest are
219 encouraged to share them with SSHWC.
220

221 **5.1 When Confidentiality is Unnecessary**

222
223 In some instances, a provision of confidentiality may be *unnecessary*, e.g., when the human
224 participant is a public figure or official spokesperson for an organization; when the data are
225 observable by anyone in a public setting; and so on. Nonetheless, researchers should normally
226 refrain from naming individuals in their written reports and other publications unless the
227 participant agrees to be named and/or other principles – for example, the accountability of public
228 figures – apply. In some instances, such research would fall under the exemptions from ethics
229 review that are listed in the TCPS.⁶
230

231 **5.2 When Confidentiality is Freely Waived by the Participant**

232
233 A provision of confidentiality may be *freely waived* by the participant when the information
234 sought is of the sort they would freely share with the researcher or anyone else, e.g., when a
235 researcher is interviewing persons in regards to their attitudes on a topic that people might talk
236 about at a party or with any stranger and the participant does not care whether confidentiality is
237 observed. In such a situation, a default expectation of confidentiality should nonetheless prevail.
238 Researchers should be circumspect about naming individuals or sharing information with other
239 individuals in the research, and would normally anonymize any written analyses or results unless
240 given specific permission to name individuals, or the participant specifically asks to be named. In
241 the latter case, researchers should consider, but not automatically grant, such a request. The role

⁵ 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.

⁶ See Article 1.1(c) on p.1-1.

242 of the REB would be to ensure that any waiving of confidentiality is done freely, and that no
243 undisclosed harms can befall the participant in the event of disclosure.
244

245 5.3 When Confidentiality is Out of the Researcher's Control

246
247 In other situations it may be *difficult* to guarantee confidentiality, such as when its provision is
248 beyond the researcher's direct ability to control. For example, researchers who do "focus group"
249 interviews where participants are sharing their views in this quasi-public forum can understand
250 and respect the sensibilities of participants in relation to their preferences for confidentiality
251 outside the group setting in any written materials arising from the interviews, but they have no
252 direct control over what the other participants in the group interview may say outside the research
253 setting. However, researchers in this situation may use the opportunity to discuss confidentiality
254 considerations, educate participants about its importance to the research process, and encourage
255 them to respect the confidentiality of others just as they would hope others would respect theirs.
256 In rare instances, researchers might consider asking participants to agree to or even to sign non-
257 disclosure agreements.
258

259 5.4 When Confidentiality is Undesirable or Disrespectful

260
261 In a fourth set of situations, providing confidentiality may be *undesirable*, or even *disrespectful*.
262 In oral history, for example, there is a strong and respectful tradition of naming participants. The
263 same is true of studies involving Indigenous Elders, where naming the individual, with his or her
264 permission, is often essential to showing appropriate respect.
265

266 5.5 When Confidentiality is Essential

267
268 Finally, in many situations confidentiality is *essential* to the generation of valid data because
269 prospective research participants will only share personal information, – hence society can only
270 benefit from that information –, if they are convinced the researcher will not reveal his/her
271 sources and that they will not be harmed because of their participation.⁷ In some instances this
272 may be because of social norms respecting the kinds of information that should remain private; in
273 other instances it may be because any divulging of identifiable information can have serious
274 repercussions for the individual within and/or outside his/her immediate family or other social
275 group.
276

⁷ 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.

277 5.6 The Decision to Disclose Personal Information Rests With
278 the Participant

279
280 Researchers submitting proposals should articulate which of the above scenarios applies to their
281 work, and the basis for their view, which presumably will be grounded in disciplinary standards
282 and some indication of the prospective participants' perspectives in relation to confidentiality.

283
284 Recognition that the provision of confidentiality is not always essential for gathering data should
285 not undermine the general expectation that identifiable information that arises from the
286 researcher-participant relationship is confidential unless provisions to the contrary are clearly
287 established and freely agreed to by the participant⁸: “[W]hen a research subject confides personal
288 information to a researcher, the researcher has a duty not to share the information with others
289 without the subject’s free and informed consent” (TCPS, p.3-1). Failing arrangements to the
290 contrary, researchers have a duty of confidentiality to research participants and should act in a
291 manner consistent with that duty.

292
293 When the information gathered is such that the participant would be harmed by disclosure, the
294 decision of whether to disclose or not lies with the participant, and can only be waived by him or
295 her.⁹ Researchers cannot make participation in their research contingent on the prospective
296 participant’s waiving privilege or any other legal rights they do or might have.

297
298

299 **6. Ethics and Law**

300
301 Our ethical obligations to participants with respect to privacy and confidentiality intermingle with
302 law in a variety of ways, some of which have been considered in the peer-reviewed literature,
303 while others await more detailed consideration.

304
305 Although one would hope that ethics and law will always coincide, the TCPS recognizes that, in
306 the current state of law, “legal and ethical approaches to issues may lead to different conclusions”
307 (TCPS, p.i-8). This is certainly so in the confidentiality area, where the law and legal decision-
308 making with respect to the confidentiality of research data varies from clear to promising to
309 ambiguous. The absence in Canadian law of any clear statute-based protections for most research
310 participants – the available protections we know of at this point are available only after the fact,
311 once the specific legal challenge is mounted – creates the possibility of an ethics-law divergence.

312
313 In order to better negotiate consistencies and understand divergences between ethics and law, we
314 suggest the TCPS should include a discussion of where and how these divergences might arise,
315 how they might be anticipated, and what ethical obligations accrue in each situation. A

⁸ 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.

⁹ 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).

316 preliminary discussion of those issues appears below. Researchers reading this report are
317 encouraged to send their comments on the adequacy and comprehensiveness of the approaches
318 suggested to SSHWC.
319

320 6.1 Existing and Possible Protections for Participant Privacy 321 and Research Confidentiality in Law

322
323 Understanding of the law and its intersection with research confidentiality in Canada is still
324 evolving, but has developed considerably within the last decade during which initial threats to
325 confidentiality from third parties have appeared in Canada and competing interests – between
326 privacy rights and concerns regarding security or previously “hidden” social problems such as
327 child abuse and sexual abuse, for example – have come to the fore. We begin by considering
328 ways that law and ethics may coincide by virtue of existing or prospective legal protections for
329 research participant privacy and confidentiality.
330

331 ***6.1.1 Statute-based Protections at Statistics Canada and for “Deemed 332 Employees”***

333
334 One group of researchers and participants who have blanket statute-based legal protection for
335 their research confidences are researchers at Statistics Canada and their participants, who have a
336 statutory privilege conferred on their work via the *Statistics Act*. Recently, this protection has
337 been expanded in a manner consistent with the *Act* by allowing Statistics Canada to designate
338 certain academic researchers “deemed employees” and allow them access to identifiable
339 (individual-level) data under certain prescribed and controlled conditions, which includes
340 extension of both the obligations and the privilege of the *Statistics Act* to the deemed researcher.¹⁰
341

342 Although there are no blanket statute-based protections that create privileges for Canadians who
343 participate in research not conducted under the auspices of Statistics Canada, there are several
344 existing or possible sources of protection for research confidentiality that do or may apply in
345 particular cases.
346

347 ***6.1.2 Possible Protections in Common Law through the Wigmore Criteria***

348
349 Research participants may be protected in common law through researchers asserting a
350 researcher-participant privilege in court. In Canada, this is done by invoking the Wigmore
351 criteria, a common law test the Supreme Court has identified as the appropriate vehicle for
352 assertion of privilege on a case-by-case basis. In making such a claim, the onus is on the person
353 claiming the privilege – the researcher, in this case, on behalf of the participant – to demonstrate
354 that s/he has met the criteria.¹¹
355

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

¹¹ 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 communications must originate in a confidence that they will not be disclosed; (2) This element of confidentiality must be essential to the full and satisfactory maintenance of the relation between the parties; (3) The relation must be one 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.

356 **6.1.3 Statute-based Protections for Some Canadians Doing Research in**
357 **the United States**

358
359 Canadian researchers doing “health” research in the United States, whether funded by the U.S.
360 National Institutes of Health or not, and researchers doing criminological research in the United
361 States that is funded by the U.S. National Institute of Justice, are eligible to apply under certain
362 circumstances for statute-based confidentiality protections in the form of “Certificates of
363 Confidentiality” (for health research)¹² or “Privacy Certificates” (for criminological research)¹³
364 that can be used to protect their data while it is in the United States. Because equivalent
365 protections are not available in Canada, it may be necessary for any identifiable data gathered
366 under these provisions to remain in the United States.¹⁴
367

368 **6.1.4 Unknown Levels of Protection from “Protection of Privacy”**
369 **Legislation**

370
371 Another area of legislation that may provide some degree of protection for research participants is
372 the Freedom of Information and Protection of Privacy legislation that now exists federally and in
373 every Province.¹⁵ But while the peer-reviewed literature now includes discussion on the
374 prospective applicability of the Wigmore criteria and of the U.S. confidentiality certificates and
375 privacy certificates to research,¹⁶ we are unaware of any similar discussion in relation to privacy
376 legislation.¹⁷
377

378 **6.2 Possible Sources of Conflict Between Ethics and Law**

379
380 There are at least three areas of potential conflict between the law and the ethical duty of
381 confidentiality to research participants:
382

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

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

¹⁴ That said, concerns exist among U.S. researchers over the implications of the *Patriot 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.

¹⁵ 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.

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

¹⁷ 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.

383 **6.2.1 Criminal Prosecutions and Civil Litigation**
384

385 Crown prosecutors, Senate Committees and various public bodies can subpoena researchers to
386 testify about crimes and/or other offences research participants may have revealed to the
387 researcher. Coroners also can subpoena researchers who they think might have information
388 relevant to an inquest. Similarly, non-governmental third parties can subpoena researchers to
389 testify about issues arising in high stakes litigation. These situations are considered in Section 7
390 below.
391

392 **6.2.2 Unanticipated “Heinous Discovery”**
393

394 Unanticipated heinous discovery occurs when researchers serendipitously learn about prospective
395 harm to an identifiable target that is outside the expected scope of their research inquiry and is so
396 serious if it were to occur that they feel ethically compelled to violate the promise of confidence
397 they offered in good faith in order to prevent the harm. Prospective conflicts with law arise
398 because they may be held liable for harm to third parties they could have prevented, as well as for
399 harms they may create if their reading of the situation is incorrect and their allegation false.
400 Ethical issues arising from this possibility are considered in Section 8 below.
401

402 **6.2.3 Mandatory Reporting Laws**
403

404 Although there is no general legal obligation for researchers to report crime they hear about in
405 relation to their research, some specific mandatory reporting laws have been enacted that do not
406 exempt researchers. These vary by jurisdiction, but may include, for example, elder abuse, child
407 abuse or “children in need of protection,” and/or spousal assault. Also, some provinces may enact
408 mandatory reporting laws that pertain to members of particular professions. See Section 9 below
409 for a discussion on the ethical implications of these laws for researchers.
410

411 In general, mandatory reporting laws and unanticipated heinous discovery involve situations
412 where the researcher's violation of confidentiality would be a matter of his or her own initiative,
413 independent of any direct external compulsion, because in many cases it is unlikely anyone other
414 than the researcher will know what the researcher knows. In contrast, subpoenas create the threat
415 of compelled revelation.
416

417 Depending on the kind of research they are conducting, researchers could find themselves
418 confronting dilemmas in any of these three areas. Historically, in the U.S. at least, it is the first
419 category — involving the possibility of subpoena and orders for disclosure — that have received
420 the greatest attention, perhaps because they are the most visible. In Canada there have been
421 considerably fewer visible conflicts thus far, all of which have fallen in the first category.¹⁸
422 However, some would argue that the most pervasive contemporary issue in ethics and law is the
423 impact on research of mandatory reporting laws.
424

425 In the sections that follow, we discuss ethical issues that arise in each of the three areas and offer
426 interim resolutions or alternatives SSHWC has developed and/or seen advanced in the literature.
427 We welcome any readers of this interim report who would like to advance alternative approaches
428 to contact SSHWC at sshwc@pre.ethics.gc.ca.
429

¹⁸ See, for example, Cecil and Wetherington (1996) and Palys and Lowman (2000).

430 7. Criminal Prosecutions and High Stakes 431 Litigation

432
433 Third parties may attempt to use legal force – typically via subpoena – in an effort to secure, for
434 their own purposes, identifiable research information that was gathered in confidence:
435

436 **In the realm of criminal law:** Crown prosecutors, Senate Committees and various public
437 bodies can subpoena researchers to testify about crimes and/or other offences research
438 participants may have revealed to the researcher. Coroners also can subpoena researchers
439 who they think might have information relevant to an inquest.¹⁹
440

441 **In the realm of civil law:** Non-governmental third parties can subpoena researchers to
442 testify about issues arising in high stakes litigation.
443

444 7.1 Protecting Confidentiality is a Shared and Proactive 445 Responsibility

446
447 Confidentiality is a core ethical principle in the TCPS and is essential to the acquisition of valid
448 data in many areas. When third parties attempt to acquire research information provided in
449 confidence, they exploit the existence of information that in all likelihood would not have existed
450 save for participants’ trust in the researcher and belief in the integrity of the research enterprise.
451 As the TCPS recognizes, “Breaches of confidentiality may cause harm: to the trust relationship
452 between the researcher and the research subject; to other individuals or groups; and/or to the
453 reputation of the research community.” (p.3-1). Third party challenges to confidentiality should
454 be resisted vigorously. The TCPS already recognizes this obligation, noting that, as a minimal
455 standard, researchers are “honour-bound” to protect “to the extent possible within the law” the
456 confidentiality they have pledged, and that researchers’ institutions should support them (p.3-2).
457

458 However important these affirmations, the ethical obligation to protect research participants,
459 research confidentiality and the integrity of the research enterprise is best accomplished if
460 resistance is seen as more than a reactive possibility. Doing so effectively is a shared
461 responsibility that also requires prevention and prepared response. The TCPS thus should express
462 not only the onus of responsibility on researchers, REBs and the institutions that employ and fund
463 them to resist third party challenges after the fact, but also should outline the precautions,
464 methods and dedicated resources that can and should be put in place ahead of time to ensure that
465 resistance is most effective. In particular, in cases where confidentiality is essential for the
466 acquisition of valid data, and the potential adverse impact of disclosure on the participant is
467 significant, SSHWC has identified the following responsibilities for researchers, Research Ethics
468 Boards, university administrations, the granting agencies and disciplinary and professional
469 associations:
470

¹⁹ 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 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.

471 **7.1.1 Researchers**

472

- 473 • should design their research in such a manner that it either (a) makes the identification of
474 individual respondents impossible by gathering data anonymously or anonymizing it at the
475 earliest opportunity; or (b) if participants remain identifiable, anticipates the Wigmore
476 criteria;²⁰ and
- 477 • should inform institutional authorities, including their REB, as early as possible if they are
478 identified as “persons of interest” or are the subject of legal action (e.g., subpoena) regarding
479 research confidentiality so that their institution of employment and kindred institutions and
480 associations can be of assistance in providing the best possible protection to them and the
481 research participants involved.²¹

482

483 **7.1.2 Research Ethics Boards**

484

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

494

495 **7.1.3 University Administrations**

496

- 497 • should be prepared to defend threats to confidentiality not only because of the moral
498 obligation they have to protect research participants, but also because defending their

²⁰ 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.

²¹ 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))].

499 interests is a defence of academic freedom, the research enterprise and their own future
500 viability;²²
501 • should develop institutional policies that direct all university-affiliated researchers to bring
502 the matter quickly to institutional attention, and direct them to a particular individual who can
503 authorize obtaining preliminary legal advice; and
504 • because institutional interests may in some ways conflict with the interests of researchers and
505 research participants, [university administrators] should ensure any legal representation of
506 researchers and participants is at arm’s length from legal representatives of the administration
507 of the institution.
508

509 ***7.1.4 The Granting Agencies***

510
511 • as creators of the TCPS and its ongoing steward, should be prepared to assist in defending the
512 standards it articulates in any way possible – e.g., organizationally, financially, as expert
513 witnesses – in order to defend the integrity of the TCPS and the research enterprise and assert
514 the rights of research participants.
515

516 ***7.1.5 Disciplinary and Professional Associations***

517
518 • should continue articulating disciplinary standards regarding confidentiality, filing *amicus*
519 *curiae* briefs and serving as expert witnesses in court on behalf of researchers who assert
520 privilege when third parties have sought identifiable research information, and promoting the
521 development of statute-based privileges commensurate with researchers’ ethical obligations
522 to protect research participant privacy and confidentiality.
523 • should consider articulating discipline-based standards for members who combine research
524 interests with professional responsibilities (e.g., clinical psychologists; research consultants;
525 educators), if these do not exist already, that address the prospective conflicts of interest that
526 can arise from their dual roles and outline appropriate alternatives for researchers to consider
527 when reconciling such conflicts.
528

529 Court decisions regarding claims of privilege make clear that the courts expect people who claim
530 privilege to behave in a manner that is consistent with the seriousness of the responsibility that
531 goes with being in a privileged relation and its commensurate duty of confidentiality.
532 Accordingly, SSHWC asks the research community to consider whether the TCPS should make
533 explicit the sets of obligations listed above. Our interim proposal is that it should. If the
534 experience of researchers in Canada and the United States over the last three decades is any
535 indication, challenges likely will arise infrequently, but when they do, there will be much at stake
536 and the courts will scrutinize every aspect of the researcher’s, REB’s and institution’s behaviour,
537 as well as the TCPS and its provisions. Researchers’ track record with the courts in both Canada
538 and the United States is a good one; in most cases the courts have recognized the importance of
539 research confidentiality to academic freedom and of academic freedom to effective inquiry, and

²² 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.

540 often have gone out of their way to protect research participants.²³ This means there is good
541 reason to be optimistic about the outcomes for research participants if a claim of privilege ends up
542 in court, but REBs and researchers must do their part to ensure the court has “good facts” on
543 which to base its decision.
544

545 7.2 The Researcher’s Dilemma

546
547 The main difficulty with the law in Canada as it pertains to research confidentiality is that, for
548 everyone other than Statistics Canada researchers and their participants, it is a law created after
549 the fact, while researchers must make their pledges to research participants ahead of time. We
550 hope the courts will appreciate and affirm our ethical duties in the completion of our academic
551 mission, but in the current state of law, even if we do all due diligence with respect to meeting the
552 Wigmore criteria, there are no guarantees. This means that, in theory at least, law and ethics “may
553 lead to different conclusions” (p.i-8).
554

555 This prospective divergence of ethics and law places researchers in the position where they must
556 make a choice at the outset as to whether they will prioritize ethics or law at the rare last instant
557 when and if the two part company. The three granting councils have made clear that researchers
558 do indeed have the right to make such a choice, and have outlined some of the responsibilities
559 that flow from those choices.²⁴ Whatever their choice, researchers and REBs are obliged to act in
560 a way that minimizes harm for the participant and maintains the integrity of the research process.
561

562 7.2.1 An “Ethics-First” Approach

563
564 Those researchers who choose an “ethics-first” strategy should understand what they are getting
565 themselves into, and the possible repercussions that may arise for them, but should also feel
566 confident that the institutions that employ them will respect their decision and do everything
567 possible to assist their legal defence. In the worst case, researchers who defy a court order for
568 disclosure can be fined and/or incarcerated for contempt of court. We are aware of two
569 researchers in the United States who have been jailed for their ethical commitment to maintain
570 research confidentiality in the face of a court order for disclosure:²⁵ Harvard political scientist
571 Samuel Popkin was jailed for 8 days in 1972 for his refusal to identify sources behind the
572 *Pentagon Papers*; and Washington State University sociology graduate student Richard Scarce
573 was jailed for 159 days in 1995 for his refusal to divulge the content of research conversations he
574 had with an animal rights activist accused of extensive vandalism of the university’s animal
575 laboratory facilities.
576

577 SSHWC accepts this defiance as an ethical approach that is an unfortunate by-product of the
578 current state of Canadian law, and enjoins research institutions to ensure that in the unlikely event
579 this worst case scenario were to occur, researchers are not penalized for their ethical observance.
580 Any fines should be paid by the institution, for example, and researchers’ employment status and
581 conditions of employment should not be affected by their incarceration; student researchers

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

²⁴ 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>

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

582 should experience no loss of status and appropriate consideration should be shown regarding the
583 completion of course requirements.
584

585 **7.2.2 A “Law-First” Approach**

586
587 The “law-first” approach begins with the researcher acknowledging that, while s/he will live up to
588 the expectation articulated in the TCPS to do everything possible within the law to resist
589 disclosure of research confidences, if, in the last instant a court of last resort were to order
590 disclosure, the researcher would comply with that order.
591

592 While the “ethics-first” approach is reasonably straightforward in its requirements, the “law-first”
593 strategy is less so because complying with an order for disclosure would appear to violate the
594 TCPS injunction to maintain research confidentiality unless the research participant gives his or
595 her “free and informed consent” (p.3-1). And as the TCPS goes on to explain, “Breaches of
596 confidentiality may cause harm: to the trust relationship between the researcher and the research
597 subject; to other individuals or groups; and/or to the reputation of the research community”
598 (p.3-1). If the effect of a disclosure were to cause the research participant harm then it would be a
599 violation of the ethical injunction to ensure that research participants are not harmed by their
600 participation in our research, and of the responsibility all researchers and research institutions
601 share to maintain the integrity of the research enterprise. It thus behoves us to consider what an
602 ethical “law-first” strategy that respects law while incurring no harm for research participants
603 would look like.
604

605 **7.3 Avoiding a Research Equivalent of *Caveat Emptor***

606
607 Generally speaking, “law-first” approaches emphasize that there are theoretical legal limits to
608 confidentiality and that any researcher who would follow legal orders for disclosure should warn
609 prospective research participants of that possibility. While the “law-first” approach is clearly an
610 ethical one, the primary danger that the TCPS and institutions should safeguard against is any
611 devolution of this approach into a research equivalent of *caveat emptor*. This would occur in its
612 most obvious and extreme form when a researcher dismisses strict confidentiality as unattainable;
613 replaces it with a complete reliance on informed consent; and asserts that violations of
614 confidentiality are acceptable as long as researchers warn participants ahead of time this might
615 occur. While this approach might be justified by interpreting the TCPS assertion that “the
616 researcher has a duty not to share the information with others without the subject’s free and
617 informed consent” (p.3-1) as legitimizing disclosure, researchers cannot pick and choose the
618 ethical principles to which they will adhere, and an exclusive emphasis on informed consent is
619 problematic to the extent it excludes or ignores other equally important principles. The dismissal
620 of confidentiality in favour of informed consent as reflected in the *caveat emptor* extreme is
621 ethically unacceptable for four main reasons:

- 622 • The TCPS recognizes that “Breaches of confidentiality may cause harm: to the trust
623 relationship between the researcher and the research subject; to other individuals or groups;
624 and/or to the reputation of the research community” (p.3-1). The *caveat emptor* approach
625 allows that harm to occur, thereby failing to meet the TCPS principle that information that
626 could cause harm must be kept confidential (TCPS, p.3-1).
- 627 • The *caveat emptor* approach appears to download responsibility for the management of
628 information to research participants. Most research participants are likely to be unaware of
629 how legal principles and procedures interact with research confidentiality; investigators

630 cannot abdicate the ethical responsibility and fiduciary obligation they have for managing
631 sensitive information and protecting participant interests.

632 • Depending on how a warning about the possibility of disclosure is constructed, it may
633 constitute a “waiver of privilege.” Investigators cannot make the waiving of rights, including
634 the right to claim privilege, a condition of participation. Doing so is a violation of the TCPS
635 principle that researchers as a minimal standard are “honour-bound” to protect research
636 participants “to the extent possible within the law.” (TCPS, p.3-2)

637 • Continuing to acquire information that benefits the researcher (through publications, fame,
638 merit increases and so on) and society (in the form of greater understanding) while divesting
639 oneself of responsibility for ensuring no harm comes to the participant is exploitative, and
640 violates what the TCPS identifies as a fundamental moral imperative: “Part of our core moral
641 objection would concern using another human solely as a means toward even legitimate
642 ends” (p.i-4).

643

644 In view of these concerns, SSHWC suggests an ethical “law-first” approach that avoids the
645 research equivalent of “*caveat emptor*” involves the following elements:
646

647 ***7.3.1 Informing Participants***

648

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

655

656 ***7.3.2 Avoiding Waivers of Privilege***

657

658 Researchers cannot require prospective participants to waive any legal rights – including the right
659 to claim privilege – as a condition of participating in their research. In particular, there is a
660 concern that any limitation of confidentiality by law might constitute such a “waiver of
661 privilege.”²⁶ Anything that would undermine the researcher’s ability to assert privilege on behalf
662 of the participant would be a violation of the TCPS injunction that, as a minimum standard,
663 researchers are honour-bound to protect research confidences “to the extent possible within the
664 law” (p.3-2).

²⁶ 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 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.

665 **7.3.3 Ensuring No Harm Can Result**

666

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

676

677 **8. Unanticipated Heinous Discovery**

678

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

683

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

690

691 **8.1 The Truth is Rarely Simple**

692

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

697

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

701

702 (b) How is one to distinguish whether the information is real or whether the respondent
703 is simply testing the researcher and/or pulling his/her leg?

704

705 (c) Who is an appropriate person to judge whether the threat is real?

²⁷ 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.”]

706

707 All of these concerns speak to the issue of competent judgment, and a recent U.S. court case
708 offers a cautionary tale. The incident occurred in Georgia, and arose when a psychologist doing
709 interviews with members of a municipal police force listened as one officer described, in
710 confidence, his fantasies of killing the police chief and other members of the force. The
711 psychologist took the description seriously, informed the chief of the alleged danger, and initiated
712 a chain of events that ended with the termination of the interviewed officer's career in policing.
713 The officer later sued the psychologist for defamation and negligence and won an award of
714 \$287,000, claiming that the psychologist over-reacted to stories that were nothing more than
715 fantasy.²⁸

716

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

726

727

728 8.2 What Prospective Harm Might Make Voluntary Disclosure 729 Permissible?

730

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

734

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

739

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

743

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

²⁸ *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.

²⁹ *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."

750 nothing less than that would justify violating a duty of confidentiality, the presence of all three
751 criteria should initiate a detailed case-by-case consideration of its appropriateness in a manner
752 they outlined in greater detail in their decision.
753

754 8.3 Enduring Obligations to the Participant

755
756 Even if the criteria are met and the decision is made to violate the confidence in order to protect
757 the third party, the matter is not so simple as merely “calling the police” and violating the
758 confidence. Rather, the Justices in *Smith v Jones* re-affirmed the ongoing obligation lawyers and
759 those who came under their privilege³⁰ have to their clients, part of which is to ensure that they do
760 not undermine their client’s right to a fair trial, and we take the obligation of researchers to be the
761 same. This implies that any violation of confidence has to be the absolute minimum violation
762 necessary to prevent the harm from occurring. And indeed, the Justices affirmed that “preventing
763 the harm” is the objective here – which could be done by any of a variety of means including but
764 not limited to calling the police – and not “jailing the accused.”

765
766 As appealing as it may be to ensure that Mr. Jones does not slip back into the community without
767 treatment for his condition, completely lifting the privilege and allowing his confidential
768 communications to his legal advisor to be used against him in the most detrimental ways will not
769 promote public safety, only silence. For this doubtful gain, the Court will have imposed a veil of
770 secrecy between criminal accused and their counsel which the solicitor-client privilege was
771 developed to prevent. Sanctioning a breach of privilege too hastily erodes the workings of the
772 system of law in exchange for an illusory gain in public safety.
773

774 8.4 Should a “Unanticipated Heinous Discovery” Warning be 775 Part of Informed Consent?

776
777 A final issue concerns whether, in the interests of informed consent, prospective participants
778 should be informed if an unanticipated heinous discovery would lead the researcher to violate a
779 pledge of confidentiality. Although there might be some instances in which researchers might
780 consider it appropriate, SSHWC advises in general against it for three main reasons.

781
782 First, researchers have no obligations to inform prospective participants about issues that are
783 outside the expected bounds of the research, and “unanticipated heinous discovery” is, by
784 definition, an unanticipated discovery. This makes a warning difficult to construct, even if
785 desired, for two main reasons: (1) it is likely impossible to outline the range of unique
786 circumstances that might lead the researcher to violate a confidence; and (2) research participants
787 might well find it bizarre and/or offensive to be warned about possibilities that have nothing to do
788 with the area of inquiry.

789
790 We also note the paradox that any requirement to limit confidentiality to account for
791 “unanticipated heinous discovery” creates. The main reason for considering the notion of
792 “unanticipated heinous discovery” in the first place is presumably because of recognition of the
793 concern we would have for some innocent third party whose victimization we serendipitously

³⁰ 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. The consultation was treated as an instance of lawyer-client privilege because it was part of the preparation of defense.

794 discover is imminent. But if we give a warning that indicates we would intervene if respondents
795 were to tell about some prospective heinous action, it becomes less likely the respondent who is
796 planning such an action will tell us of his/her intentions, with the paradoxical result that our
797 warning makes it more likely the prospective victim will indeed be harmed.

798
799 And finally, unanticipated heinous discovery is an incredibly rare event. In that context, giving
800 warnings because of the remote possibility of some heinous revelation falling in our laps is the
801 wrong emphasis and contrary to the fiduciary duty we have to protect participant interests.
802 Information is far better given in the opposite direction – where researchers consider, and
803 research participants hear, how important confidentiality is to the research enterprise, and the
804 considerable lengths we will go to defend it.
805

806 8.5 A Draft Policy

807
808 On the basis of the above considerations, we suggest the following guidelines for the research
809 community's consideration as guidelines for "unanticipated heinous discovery."³¹
810

811 **Draft Guidelines for "Unanticipated Heinous Discovery"**

812 **Preamble**

813
814
815
816 The *Tri-Council Policy Statement (TCPS p. i-5)* holds that privacy and confidentiality are
817 core research ethics principles. However, the *TCPS* recognizes that research ethics
818 principles are not absolute; they interact with various other ethical and legal obligations.
819

820 With regard to confidentiality, it is conceivable that, on very rare occasions, a researcher
821 might violate a guarantee of confidentiality in order to satisfy what they believe to be a
822 higher ethical obligation, such as saving someone's life. When such a possibility is
823 outside the terms of reference for the research, this is a problem of "unanticipated
824 heinous discovery." What should a researcher do if, out of the blue, a research participant
825 says that they intend to harm a third party? What degree of harm justifies violating
826 confidentiality? What ethical guidelines should researchers follow in such cases? Are
827 there any legal guidelines that need to be taken into consideration?
828

829 When it comes to law, there are no North American cases dealing with the legal
830 obligations of researchers confronting heinous discovery. However, there is some case
831 law in Canada and the U.S. pertaining to doctors and lawyers – both of whom are
832 ethically and legally bound to maintain confidential relationships with their clients –
833 when a patient or client divulges that they intend to murder someone. In the U.S. at least
834 one patient made good such a threat.
835

836 In Canada the most significant case pertaining to how doctors and lawyers should deal
837 with unanticipated heinous discovery is *Smith v. Jones* ([1999] 1 S.C.R. 455) where the
838 Supreme Court of Canada describes three criteria comprising the "public safety

³¹ 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.

839 exception” to solicitor-client privilege. These unanticipated heinous discovery guidelines
840 for researchers are adapted from this case.

841

842 **The Public Safety Exception as a Matter of Research Policy**

843

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

847

848 1) *Seriousness*: Is there a risk of serious bodily harm or death?

849 2) *Imminence*: Is the danger imminent?

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

851

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

857

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

863

864

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

868

869 **9. Mandatory Reporting Laws**

870

871 **9.1 Diverse Approaches to Mandatory Reporting**

872

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

883

884 The existence of mandatory reporting laws creates for both groups of researchers a conflict of
885 interests they must resolve ahead of time when it is reasonably plausible they will hear about
886 reportable behaviour in their research. The researcher who would willingly report behaviour that
887 is subject to mandatory reporting provisions has interests at odds with the participant they have a

888 duty to protect; the researcher who disagrees with mandatory reporting provisions must
889 nonetheless deal with their existence. The general principle that applies to both is that they must
890 attempt to resolve the conflict before undertaking the research. The ways this is done may vary
891 according to the disciplinary standards and professional affiliation of the researchers, and we
892 invite researchers who have had to deal with this dilemma to inform us of their experiences and
893 its impact on their research.³²
894

895 9.2 Direct Questioning of Reportable Behaviour

896
897 SSHWC cannot understand how any researcher could justify asking participants directly and
898 gathering identifiable data about behaviour they would knowingly report. Gathering such
899 information without informed consent would be deceptive and would undermine the integrity of
900 the research enterprise by equating research with a policing function. Although stated in the
901 TCPS in relation to international research, SSHWC believes it is equally true for research in
902 Canada that it is, "... unethical for researchers to engage in covert activities for intelligence,
903 police or military purposes under the guise of university research. REBs must disallow any such
904 research." (TCPS, p.1-12). A similar injunction appears on p.2-4: "Researchers should avoid
905 being put in a position of becoming informants for authorities or leaders of organizations."
906

907 Gathering reportable information *with* informed consent would seem exploitative and, in any
908 event, any identifiable data surely would be of questionable validity. The only acceptable way
909 that we can think of for the reporting researcher to gather such information would be for him or
910 her to gather the data under conditions of complete anonymity, so that neither the researcher nor
911 anyone else could ever connect any reportable behaviour to any particular individual.
912

913 9.3 Where Touching on Mandatory Reporting Laws is Plausible

914
915 In a second situation we can envision circumstances in which researchers might wish to ask
916 questions in the general area of a reportable behaviour – interviewing parents about their child-
917 rearing practices, for example – where it is foreseeable that some respondents might describe
918 practices that would come under mandatory reporting provisions. SSHWC believes it is important
919 in such circumstances for participants to be made aware of both the mandatory reporting
920 provisions and the researcher's interpretation of them. In British Columbia, for example, the
921 mandatory reporting law regarding ongoing victims of child abuse requires persons to report
922 when they have "reasonable grounds to believe that a child is in need of protection." The
923 researcher should consider what sort of circumstances would lead them to believe that a child was
924 "in need of protection," and what sorts of evidence would constitute "reasonable grounds" for
925 that belief, and explain their view of those reporting triggers to prospective participants. Legal
926 opinions regarding the more liberal and conservative interpretations of these terms would benefit

³² 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 on page 2-8, "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."

927 both groups of researchers in ensuring that both made every effort to operate within the law while
928 maintaining their ethical obligations to participants. We welcome researchers who have faced
929 such situations to inform us of any other resolutions they believe are appropriate.
930

931 9.4 When Third Parties Are Affected

932
933 Matters become more complicated when it is a third party who would be affected by the
934 mandatory reporting requirement, and not the participant, who in some instances might be the
935 person the researcher believes s/he would be protecting by reporting the third party. For example,
936 a medical researcher interviewing patients about the treatment they have received might be told of
937 events that constitute negligent or abusive treatment that s/he is obliged to report. Alternatively, a
938 researcher who interviews adolescents about their relations with adults might conceivably hear
939 about situations that lead them to believe the adolescent is in need of protection.
940

941 SSHWC has seen no informed legal analyses of these situations and suggest they would be
942 useful. Is a one-sided view of adverse treatment sufficient to create “reasonable and probable
943 cause” for believing a minor is “in need of protection”? If the participant is the one with the
944 “reasonable and probable” belief is it appropriate for the researcher to inform them of their
945 alternatives and leave reporting to them? How should researchers deal with what is effectively
946 “hearsay”? A balanced legal analysis of these ethical issues would be most welcome, as would
947 any information that is available regarding participant perspectives in different contexts. In the
948 interim, researchers treading into such areas are obliged to inform themselves of the legal issues
949 that may affect them, the disciplinary standards associated with their research, and consider what
950 their ethical resolution to those difficult dilemmas will be prior to engaging in the research. As a
951 minimum, there should be a full and frank discussion with the participant of what the researcher
952 believes his/her reporting requirements are, what sorts of incidents in the eyes of the researcher
953 would trigger that reporting, and whether the researcher would heed, consider, or ignore the
954 views of the participant in such an eventuality.
955
956

957 10. Affecting the Development of Law Through 958 Ethical Approaches

959
960 In addition to noting that law and ethics can “lead to different conclusions,” the TCPS also
961 reminds us that, “[a]lthough ethical approaches cannot preempt the application of the law, they
962 may well affect its future development” (p.i-8).
963

964 A literature now exists regarding the interaction of law and ethics when our ethical obligations to
965 protect research confidentiality are challenged by third parties. It tells us that when third parties
966 challenge research confidentiality, and researchers and their institutions resist through an
967 assertion of privilege, the courts will inspect every aspect of their behaviour, and of their
968 institutions’ behaviour, to determine whether the researcher and the research enterprise of which
969 we are a part have acted in a manner that is consistent with the possession of privilege. It also
970 tells us what the research community needs to do in order to produce good “case facts” that will
971 maximize the likelihood of courts generating decisions and recognizing privilege in a way that is
972 most beneficial to research participants, researchers, and the Canadian public. Much of that
973 advice appears in this document.
974

975 Other areas remain far more ambiguous, however, and we can only encourage Canada's research
976 communities to contribute to those discussions regarding the impact and ethics of mandatory
977 reporting laws, for example, as well as the creation of an interpretive guide that explains what
978 those laws mean in the course of our everyday lives as researchers and professionals. Much also
979 needs to be known about the role that privacy law and legislation might play in the protection of
980 research confidentiality. We encourage the research community to assist SSHWC in the short
981 term by sharing their observations and perspectives on these issues, and helping all of us in the
982 long term by contributing to the literature that will influence development of law to better reflect
983 ethical perspectives in future.
984

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1023 responses that are associated with the researcher and their institutions doing "everything possible" to
1024 protect research confidentiality. Although some of the advice is specific to the U.S. legal system,
1025 much of it is applicable to Canada. The article is online at
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