"Without Trust, Research is Impossible":
Administrative Inertia in Addressing Legal Threats to Research Confidentiality

by
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The author, whose name appears on the title page of this work, has obtained, for the research described in this work, either:

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or

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Abstract

The last two decades have seen the development of formalized federal research ethics policies in countries such as the US, Canada, Australia, and New Zealand. The focus of these policies has been researchers; comparatively little attention has been paid to the university administrations who provide the context in which those review bodies operate and whose resources are integral to protecting research participants when external threats arise. Far from being staunch defenders of academic freedom and protecting those who participate in research, university administrators in Canada have more commonly revelled in "edgy" research until the subpoena arrives, and then promptly thrown the researchers under the proverbial bus. In Canada, the federal ethics policy now requires university administrations to "support" their researchers when a legal threat arises, and "encourages" them to have policies in place that articulate how they will do so. Two years later, few policies exist. This thesis will review the record of administrative support for cases where research confidentiality is threatened, and present the results of a national survey of REB chairs, administrators, and REB staff, as to the current state of these policies and the impediments to their creation.

Keywords: researcher indemnification; research confidentiality; Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); research ethics
Dedication

This thesis is dedicated to Mom, who has been my biggest supporter. While in many cases individuals claim that their Mom is indeed the best, in my case this hypothesis is supported by the data. Thanks Mom!
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Thanks to my good friend and senior supervisor Ted Palys for his ongoing advice, critical eye, and good ideas. I also would like to acknowledge Ted and his long-time colleague John Lowman, who have been fighting for the protection of research confidentiality for decades, laying years of groundwork for this current research. Thanks are also due to Tamara O'Doherty for her role as supervisor, and Susan Zimmerman for participating as the external examiner on my thesis committee. Finally, I would like to express my appreciation to the SSHRC Small Grants programme for funding a portion of this research through a grant to Ted Palys, and the SSHRC Fellowship program for its personal support through the Joseph-Armand Bombardier CGS Master's Scholarship.
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Chapter 1. Introduction

Academic inquiry requires that we balance several principles: academic freedom, adherence to ethical codes, and a duty to protect the communities and people who participate in our research. Noted American criminologist Marvin Wolfgang (1981) maintains researchers should adhere to strict ethical codes which include “classical issues related to protection of human subjects, invasion of privacy, confidentiality of records and interviews, accessibility to data, and immunity of researchers from prosecution” (p. 346). The protection of both researchers and the data they collect under assurances of confidentiality is essential to facilitate academic research. Professional associations in most disciplines, from psychology to health, list confidentiality as among the most important principles of ethics. Through a mixed methods research design, this thesis examines how research institutions across Canada are currently protecting their researchers and research participants through an examination of their current policies, (or lack thereof), regarding third-party attempts to disclose information collected under conditions of confidentiality. We also examine current impediments faced by institutions attempting to create researcher indemnification policies, as well as current practices and procedures pertaining to how various members of the research community are currently addressing challenges to research confidentiality. What we have found is that the current state of research confidentiality is a precarious one; although the federal Secretariat on Responsible Conduct of Research has made clear that institutions have an obligation to support their researchers by providing independent legal support in their defence of research confidentiality, few administrations at research institutions have developed policies to outline how to engage that support when and if a challenge to research confidentiality were to arise. Given their poor record in supporting researchers thus far, such policies would go a long way to making clear that institutions will no longer abandon their researchers when challenged. Good research not only requires participants to trust the researchers they are working with, but it also requires researchers to trust the administrations who are overseeing that research. Without trust, research is impossible.
1.1. Academic Freedom

Machlup (1955) defines academic freedom as protection from authority sanctions and pressures that inhibit research, teaching, or publishing by creating apprehension and anxiety in the minds of academic researchers. Academic freedom is most likely to be threatened when research veers into territory deemed controversial by society and/or university administrators. However, rather than viewing academic freedom as a privilege reserved for those in academia, Machlup (1955) argues “it is the people at large who have a right to learn what scholars may succeed in finding out if they are left free and secure from reprobation” (p. 758). Historically, the greatest threats to academic freedom have been based in political and religious interference, but modern academics are arguably facing new challenges despite the rise of liberal democracies (Minerva, 2014). Minerva (2014) argues the media now pose the greatest threat to academic freedom, particularly the media as facilitated by the Internet. In the past, research would be published in academic journals, largely unread by the general public. However, current trends have seen the media publishing portions of scholarly articles, making them available to a considerably larger audience. Much of this can be attributed to a culture of community engagement, a concept which has become very popular in research institutions.

In Canada the three federal granting agencies, the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada (NSERC) and the Social Sciences and Humanities Research Council of Canada (SSHRC) strongly encourage both knowledge mobilization and open access among their researchers stating:

As publicly funded organizations, the Agencies have a fundamental interest in promoting the availability of findings that result from the research they fund, including research publications, to the widest possible audience, and at the earliest possible opportunity. Societal advancement is made possible through widespread and barrier-free access to cutting-edge research and knowledge, enabling researchers, scholars, clinicians, policy-makers, private sector and not-for-profit organizations and the public to use and build on this knowledge...Open access enables researchers to make their research results freely available to the domestic and international research community and to the public at large thereby enhancing the use, application and impact of research results. (NSERC, “Policies and guidelines,” 2014)
1.2. Academics as Experts in Court

The use of academic researchers as experts in court has also brought research to a much broader audience. The admissibility of expert opinion in Canada is determined by two components: it requires that the intended expert has the qualifications to take on such a role, and the judge's cost-benefit analysis regarding whether the expert's opinion will be of probative benefit or overtly prejudicial (Beech, 2015). The qualification component is comprised of four parts which include relevance, necessity in assisting the trier of fact, absence of an exclusionary rule, and a determination that the expert opinion offered into evidence is from a truly qualified expert (Beech, 2015). The use of academics as experts in litigation by both defendants and plaintiffs requires judges to decide which expert is the most credible (Lowman, 2016). The race for credibility between opposing parties requires some investigation into the methods, research, and analysis of the provider (often in the form of their research data). While this can be done without violating the confidentiality of research participants, this is not always the requesting side’s preference; there have been several cases where confidential data was pursued that did not have identifiers removed, and others where the actual identities of participants were sought.

The use of social scientists as expert witnesses has increased in recent years, especially in the context of challenges to the Canadian Charter of Rights and Freedoms. These Charter challenges shape and define how the basic human rights of Canadian citizens are protected. In R. v. Bedford (2013), for example, each court, from the trial level to the Supreme Court of Canada, relied heavily on expert testimony from researchers whose research confirmed that Criminal Code prohibitions, including living off the avails of prostitution, bawdy houses, and public communication for the purposes of prostitution, forced sex workers out of public spaces and into remote areas where the likelihood of their victimization or death was greatly increased (Lowman, 2016; O'Doherty, 2011). Another example of a Charter case that relied on the expert testimony of researchers centred on Vancouver’s safe injection site Insite, which sought immunity from federal drug laws to improve the health and safety of intravenous drug users. After hearing the expert testimony in this case, which included evidence purporting public health benefits, the Supreme Court ruled that the closing of Insite would also be a contravention of Section 7 of the Charter (Andreson & Jozgahi, 2012). Both trials
received global media attention, bringing the academic research that helped decide these cases to millions of viewers and readers who were following these landmark decisions. This trend has implications for researchers poised to engage as experts in court. In some recent cases research confidentiality has been threatened, as will be discussed further in this thesis. This has had a chilling effect on research.

1.3. Confidentiality

The concept of confidentiality is central to the maintenance of numerous professional relationships: lawyer/client, doctor/patient, journalist/source, clergy/penitent and researcher/research participant. In the case of lawyers and clients, communication that takes place between the individuals in that relationship is protected through categorical protections in Canada, and these communications do not have to be disclosed in a court of law (Canada Evidence Act, 1985). In other cases, while there is a professional duty to maintain confidentiality, no such categorical protections exist. The need for categorical protection of communications of individuals in certain relationships is obvious. Without guaranteed confidentiality accused persons may not be forthright with their counsel, resulting in poor legal advice and judicial outcomes. For this reason, such categorical protections are deemed appropriate under Canadian law, yet there are no similar provisions for the communications of research participants.

The field of criminology clearly illustrates the need for confidentiality in research. Would criminals share their unique experiences and reasoning for committing crimes with researchers who offered them no guarantee of confidentiality? Would the police be forthright with researchers who seek to understand their real word practices if the researchers would freely share identifiable information\(^1\) with the officers’ superiors or the broader citizenry? Probably not. Criminal ethnographies are based on the traditions of anthropological research wherein researchers would undertake fieldwork, typically in small Indigenous societies (Putt, 2014). For the criminological ethnographer, communities are not simply relegated to people sharing an ancestry and region, but also include people of likeminded ideologies and subcultures (Putt, 2014). A community could be a group of drug users, people facing the same health issues, or people engaged in

\(^1\) Of course researchers gather information because they wish to disseminate it. The ethical obligation is to ensure that this sharing is done without identifying sources or providing information that would make any individual or recognizable group identifiable.
similar deviant or illegal activities. The study of subcultures through ethnographic community-based research currently includes subjects from assisted suicide to prostitution. Often it is those among society’s most vulnerable and marginalized populations who participate in this research, and these individuals require the highest standard of care and protection of the personal information they share, but wish to remain confidential. It is difficult to comprehend how a researcher could acquire phenomenological insight into these subcultures without an unequivocal guarantee of confidentiality being made to research participants. Without such a guarantee, social science’s ability to contribute to policy creation and the accumulation of knowledge related to crime and deviance would be greatly diminished. A researcher could offer a participant limited confidentiality (up until a subpoena arrives), which a participant may agree to – but in effect, this is simply downloading the responsibility to the research participant (Lowman & Palys, 2007). Rather than expecting participants in our research to take on that responsibility, it is our ethical obligation to maintain relationships of trust in which researchers operate with the best interests of their participants in mind.

Seminal ethnographic research that emerged from the Chicago School such as Sutherland’s (1937) *The Professional Thief* remain highly regarded in criminology. An unexpected revelation made through Sutherland’s (1937) research was that professional thieves go about their work much like members of any other profession. Thrasher’s (1927) *The Gang* gave society a glimpse into crime and deviance from an insider’s perspective, exposing the role neighborhood disorganization played in the creation of gangs. Without intimate knowledge of the subjects and communities facilitated by a researcher’s commitment to confidentiality, such revelations may never have been made. Today ethnographers still engage in research that involves immersion into subcultures, requiring a high degree of trust between researchers, and those who invite researchers into their communities. To preserve this trust researchers should anticipate requests for confidential information from third-parties pertaining to their participants and be very clear on how such requests will be responded to.

Subculture research continues today, tackling some of our most troubling and controversial current issues, such as terrorism. In “Functionality of Radicalization: A Case Study of Hizb ut-Tahrir,” Farhaan Wali (2016) described how he engaged in a series of complicated negotiations with the leaders of the Hizb ut-Tahrir, a prominent radical Islamist group in London, to explore the transformative feature of radicalization
through studying their members in their natural surroundings. Dingwall (2008) also speaks to the utility of research methodology that favours this kind of close and extended interaction between researchers and participants, and suggests these research methods are losing popularity because of “regulatory creep” that is concerned not with the safety of research participants, but with institutional risk management.

In the contemporary world, citizens depend upon a great deal of expert knowledge in order to make good judgments about each other and about the social institutions that they encounter. The quality of that knowledge depends crucially on free competition between information providers. If what has traditionally been the most disinterested source of information, the universities, becomes systematically handicapped in that competition, then all citizens lose out. When we give up doing participant observation with vulnerable or socially marginal groups because of the regulatory obstacles, then a society becomes less well-informed about the condition of those who it excludes and more susceptible to their explosions of discontent. How helpful is it when the only ethnographers of Islamic youth in the UK are undercover police or security service agents? (Dingwall, 2008, p. 10)

1.4. Third-Party Attempts to Obtain Confidential Research through Threat or Force of Law

In Canada, it is rare third-parties have asked the courts to force researchers to provide data collected under a pledge of confidentiality; there are only four known cases, but the three most recent cases occurred in relatively quick succession, suggesting this phenomenon may be on the rise. What is not known is how often confidential research has been turned over to a third-party due to pressure from investigators before the formal administration of legal force. Additionally, it is unknown how many researchers have eschewed engaging in highly sensitive, ethnographic or longitudinal research because of lack of confidence in their institution’s commitment to confidentiality at the hands of “regulatory creep.” In 1976, a survey regarding subpoenas was conducted among academics in the United States and three-quarters of respondents expressed their belief that improved legal protection of research data would make them more willing to work on research projects (O’Neil, 1983). Half of the respondents said indemnification from subpoenas would make them more likely to participate in controversial research (O’Neil, 1983). When third-parties have used legal mechanisms to try and acquire confidential research data in Canada, it has resulted in confusion and uncertainty when researchers look to their institutions for assistance.
1.4.1. Russel Ogden

The first instance of a legal attempt to obtain confidential research by a third-party in Canada occurred in 1994 when the Vancouver Coroner subpoenaed the research of Simon Fraser University (SFU) MA criminology student Russel Ogden (Lowman & Palys, 2000). Within his research data were interviews with people who had participated, or assisted with, the euthanasia or suicides of people who were ill with HIV/AIDS (a highly controversial topic and deadly disease at that time). The Vancouver Coroner was interested in uncovering the identity of a deceased unknown female suspected of voluntarily ending her life with the aid of a physician. Ogden and two journalists who had published an article about his research were called to testify at the inquest and asked to reveal the identities of their sources and research participants; all refused to do so (Lowman & Palys, 2000). Ogden was happy to testify about his research findings but was not willing to identify any of his participants because he had guaranteed their identities would be kept “absolutely confidential.” However, as an academic researcher, the confidentiality of his communications with his research participants was not automatically protected under the law (as it would have been in the case of a categorical protection) (Lowman & Palys, 2000).

Lacking statute-based protection, Ogden tried to assert privilege of the communications between himself and his participants through the common law Wigmore test, which the Supreme Court of Canada has recognized as the appropriate vehicle for assessing claims of privilege on a case-by-case basis (Lowman & Palys, 2001). In the application of the Wigmore test, the value of the confidence is weighed against the injury its dissemination would cause (Wigmore, 1905). Unfortunately, SFU was unwilling to publicly support Ogden’s legal battle for fear of appearing to endorse assisted suicide (Lowman & Palys, 2000). Ogden persisted nonetheless, and convinced the Coroner that he had met the criteria set out in the Wigmore test and thereby was not ordered to violate his promise of confidentiality to participants (Lowman & Palys, 2000). Ogden, disillusioned by his perceived abandonment by his institution despite completing degree requirements and following institutional policies to the letter, then sued SFU for breach of contract and requested they pay his legal fees (Blomley & Davis, 1998). Although the court ruled against him, saying that it was within the university’s discretion to decide when and if they would engage in litigation, the presiding judge lambasted SFU’s
administration in an *obiter dictum*, calling the university’s defense of academic freedom “hollow and timid” and explaining further that,

> It is self-evident that the rule of law includes the right to determine what the boundaries or the extent of academic privilege might be by way of a challenge in court. . . It is hard to understand how an institution of higher learning, engaged in very important social research, would be thought less of because it undertook to determine the boundaries of academic privilege, when the existence of that privilege is what made the research possible in the first place. The questions of the coroner to Ogden were a direct challenge to the academic freedom and privilege that were so necessary for the research that had been approved by the University. When, because of the possibility of bad publicity, the University turned its back on the researcher who was trying to uphold the standards that the University itself had set, it risked much harm to the reputation of the University and its ability to conduct this type of sensitive research. *(Russel Ogden v. Simon Fraser University, 1998, p. 24)*

Subsequently, on October 15, 1998, SFU President Jack Blaney announced that SFU would reimburse Ogden for his legal fees and lost wages, and wrote Ogden a formal letter of apology *(Palys & Lowman, 2014)*. Although the university’s initial lack of responsibility in response to the subpoena remains an unsavoury addendum in SFU’s past, more recently SFU has shown national leadership on this issue, pledging also to indemnify future graduate students in similar situations. In doing so, SFU became the first university in Canada to give graduate students guaranteed legal protection when research confidentiality is challenged *(Palys & Lowman, 2014)*.2 A memo released by SFU’s Dean of Graduate Studies in 2007 outlined:

> Where a graduate student, who is a candidate for a degree, undertakes in good faith research approved by the University under faculty supervision, and where that individual’s academic freedom is challenged or compromised by an external body, the University has an obligation to provide legal advice, representation and/or indemnification to him/her in defending against those actions… Where there is a dispute between a graduate student and the University regarding the application of this policy it will be referred to a three-person ad hoc subcommittee of the Senate Graduate Studies Committee which includes at least one student. The decision of this subcommittee will be final. *(J. C. Driver, personal communication, March 5, 2007)*

After the Ogden debacle, in 2001 Canada’s federal granting agencies released the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*

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2 Legal indemnification for faculty members was already included in the Collective Agreement between the university administration and faculty association.
(TCPS), replaced by the TCPS 2 in 2010, and further revised in 2014 (Canadian Institutes of Health Research et al., 2014). Article 5.2 of TCPS 2 states researchers must “avoid being put in a position of becoming informants for authorities or leaders of organizations,” while Article 5.1 states that in situations where a third-party is seeking confidential information from a researcher through force of law, the institution is required “to support their researchers in maintaining promises of confidentiality” (Canadian Institutes of Health Research et al., 2014, p. 61).

1.4.2. Chris Bruckert and Collette Parent

The second case in Canada in which a third-party attempted to seize confidential research through legal means occurred when a former research assistant of Professors Chris Bruckert and Colette Parent recognized accused murderer Luka Rocca Magnotta, who was the subject of an international manhunt, as a former research participant (Palys & Lowman, 2014). Magnotta had been interviewed about his role as a sex worker for a study involving male escorts (Palys & Lowman, 2014). While the research assistant did not claim to have any knowledge of Magnotta’s crime or whereabouts, he told Montreal police he recognized him from interviews he had conducted with him for a SSHRC-funded prostitution study five years earlier (Shuchman, 2014).

Professors Bruckert and Parent were then contacted by police and asked to turn over the transcripts of the interviews (Shuchman, 2014). Bruckert responded that there was no way for her to know if it was in fact Magnotta who had been interviewed, because her prostitution study was conducted under strict confidentiality protocols; research participants had been assigned pseudonyms which were used by the research assistants to sign consent forms on the participants’ behalf so that they could not be identified by their handwriting (Shuchman, 2014). The interviews were taped, transcribed with any obvious identifying information redacted, and then the tapes were destroyed, along with the research participants' real names, pseudonyms and email addresses (Shuchman, 2014). However, the former research assistant working on the study remembered Magnotta’s pseudonym of “Jimmy” and relayed this to the police who were eager to acquire the “Jimmy” transcripts and issued a search warrant to do so (Shuchman, 2014). Bruckert was not willing to hand over the data, believing this to be grossly unethical and in violation of the commitments she had made, and the obligations she felt to her participants (Shuchman, 2014). The University of Ottawa (U of O) found
itself in a situation like the one SFU had been involved in years previous, and responded in much the same manner: by offering a pat on the back and a few hundred dollars for legal advice and calling that "support."

Like Ogden, Bruckert was not satisfied with the level of support she received from her institution, and the Canadian Association of University Teachers (CAUT) stepped in to fund the defence while waiting for the U of O to live up to its responsibilities under Article 5.1 of the TCPS 2 (Shuchman, 2014). CAUT hired lawyer Peter Jacobsen, an expert in litigation involving journalist/source privilege, to prepare their case (Shuchman, 2014). Jacobson invoked the Wigmore criteria, and Bruckert and Parent's case-by-case claim for privilege was successful. Legal expenses ended up totalling nearly $300,000, considerably more than the U of O had offered (Shuchman, 2014). In consideration of this, a complaint was lodged with the Secretariat on Responsible Conduct of Research against U of O for failing to abide by the regulations in the TCPS 2, and it was only after this complaint was investigated that the U of O relented and reimbursed CAUT for half of Bruckert and Parent's legal fees (Palys & Lowman, 2014). The Ogden and Bruckert and Parent cases brought to light the fact that university administrators are not always staunch defenders of the confidentiality of the individuals who participate in their institutions’ research, particularly when that research is centred on topics that are deemed by the public as illicit or immoral.

1.4.3. Greta Bauer

The third case in Canada arose in Quebec. This research was conducted by Dr. Greta Bauer, an epidemiologist and biostatistician with the Schulich School of Medicine and Dentistry at Western University, and was described in an article by Diane Peters (2017a) in University Affairs. This case came about when the Centre for Gender Advocacy challenged Quebec's rules regarding how and when transgender individuals could legally change their genders on government documents. Bauer had done the first comprehensive national study of transgendered individuals and was asked to serve as an expert witness in the case. The defendants' counsel demanded access to Bauer’s research data that detailed how suicide risk was lowered for people whom had their gender identity updated on official documents – information that had been gathered under conditions of confidentiality. Bauer was not willing to break that confidence. Within the data was information such as postal codes and participants’ ages, which could lead
to the exposure of the identities of her participants. Bauer received immediate support in
the form of legal representation from the Centre for Gender Advocacy; her institution
also offered their financial assistance should an appeal call for further legal
representation (which was not required). Western’s vice-president of research wrote a
letter to the court which stated “we have to protect our research subjects. If we fail to do
that, research on these groups won’t get done. If this becomes the standard operating
mode of courts, entire areas of research are going to dry up” (as cited in Peters, 2017a,
para. 8). The case, Center for Gender Advocacy v. Quebec (2016), was resolved in
Bauer’s favour using the application of the Wigmore test.

1.4.4. Marie-Ève Maillé

A fourth case in Canada, which was the most recently resolved, also occurred in
Quebec. PhD student Marie-Ève Maillé had conducted research around a wind farm in
Quebec in 2010, and during her research had interviewed 93 individuals from the
surrounding community regarding their opinions on the matter (Kondro, 2016). The
interviews were held under the condition of confidentiality, allowing participants to speak
honestly about their neighbours and community without fear of negative consequences
(Kondro, 2016). In 2012, some of these community members filed a class action lawsuit
against the company responsible for the wind farm, Éoliennes de l’Érable (Kondro,
2016). Maillé had planned to be an expert witness for the plaintiffs, until the lawyers for
the defendants demanded access to her research, including the information she had
promised her participants would remain confidential (Kondro, 2016). With the Université
de Quebec à Montréal (UQAM) nowhere to be found – it is not clear at this time whether
her initial inquiries to the university were simply miscommunicated or ignored – Maillé
enlisted the aid of a lawyer who offered to help pro bono (Peters, 2017b). It was not until
months later, when the case started to be reported in the media and academics were
signing petitions calling for UQAM to defend Maillé and her participants, that UQAM
finally offered to provide legal support (Peters, 2017b). Expressing her frustration with
the situation, Maillé stated “It’s like open season for companies to come in and ask for
data from scientists. If they approach someone who can’t take the hassle that person
might just say, ‘Go ahead, take the data and leave me alone’” (as cited in Peters, 2017b,
para. 13).
These most recent cases, where confidential data has been requested from researchers who take on the role of expert witnesses in court, show a troubling trend. Both Bauer and Maillé were deemed qualified to meet the criteria set out for expert witnesses, however the threat to their participants’ research confidentiality when attempting to assist the trier of fact can be regarded as an unfair sacrifice these researchers potentially had to make. The latter two cases go beyond third-party attempts to obtain confidential data to solve crimes, thus opening the threat to research confidentiality to multiple areas of research, and numerous kinds of judicial proceedings outside of the criminal context. This is consistent with what has been seen in the more litigious United States, where threats to research confidentiality cross all sorts of disciplinary boundaries and involve both civil and criminal cases (Palys & Lowman, 2014).

1.5. Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2)

Acknowledgement of researcher/research participant privilege has now been recognized in three Canadian court cases (as well as Coroner’s Court), but must still be invoked and proven on a case-by-case basis. All institutions who receive federal funding must operate under the principles and guidelines of Canada’s three major granting agencies: SSHRC, CIHR and NSERC (Whittaker, 2005). In order to receive funding from the granting agencies, all Canadian research institutions must abide by the Agreement on the Administration of Agency Grants and Awards by Research Institutions (Government of Canada, 2016). Included in the Agreement is the institution’s duty to follow the guidelines in the TCPS 2, whether a particular project has federal funding or not. Within these rules is the shared “duty” of researchers, REBs, and institutions to protect research participant confidentiality (Canadian Institutes of Health Research et al., 2014). Article 5.1 states that the institution is required “to support their researchers in maintaining promises of confidentiality” (Canadian Institutes of Health Research et al., 2014, p. 61). A more recent interpretation of Article 5.1, released by the Interagency Advisory Panel on Research Ethics (PRE) after the failure of U of O to adequately support Bruckert and Parent explains that “support” involves financial support, (not simply offering a verbal acknowledgement of support), and that the institution must
assist the researcher to obtain independent counsel (PRE, 2015, “Privacy and confidentiality”).

Given that the current law in Canada places the onus on researchers to demonstrate to the court that they meet the Wigmore criteria – a case-by-case test used by the courts to determine whether there is a privileged relation the court should respect – Canadian researchers must rely on their institutions to assist them in upholding the ethical principles of their disciplines, which includes adhering to the policies outlined in TCPS 2. PRE has clarified the procedure required under TCPS 2 when third-party attempts to procure confidential data are made:

Each institution establishes policy or procedures that implement those guidelines in a manner that is suited to its own individual needs and resources ...The policy should include an explanation of the nature and the scope of the support, a mechanism to determine the level of support in individual cases, the source of the funding (e.g., dedicated fund, insurance, agreement with professional association) and any other relevant criteria. The institution should establish such a policy in collaboration with its researchers. (PRE, 2015, “Privacy and confidentiality”)

The reasoning behind the granting Agencies’ encouragement of the development of policies protecting research confidentiality is simple: it is important that a researcher has immediate access to independent legal advice, offered with the best interest of that researcher (and their participants), in mind. The policy itself, though not required, is intended to ensure that institutions are in a position to provide immediate support to their researchers with a clear plan as to how to do so, to ensure that those researchers are able to make informed choices as to how to proceed. Creating a policy sends a message to researchers that they can trust their institutions to be there to help them uphold research confidentiality. In light of the history of institutional responses to threats to confidentiality, this is an assurance most researchers would welcome. Having a policy in place to support researchers would prevent repeating the unpleasant scenarios that have resulted from bad decisions made on behalf of administrations in the past.

The TCPS 2 makes REBs responsible for ensuring ethical probity, and confidentiality is a core ethical principle; this thesis sought to determine just how widely the admonition to develop a protection policy has been followed, and what additional tactics both REBs and researchers have employed to further bolster research
confidentiality. As legal intrusions into research confidentiality have become more common in Canada, the implications for participants and the research enterprise are that they are open to litigious threat which could result in confidential information about research participants being made public. How many Canadian institutions have followed the encouragement of the TCPS 2 and created and implemented policies to support researchers when third-parties seek confidential data through the threat or force of law? What are included in these policies? In regard to institutions who may have formalized these policies, how did they go about creating them, under what context, and what were the challenges they faced during the creation and implementation process? Regarding institutions that do not have policies in place, what, if any, additional steps are being taken by members of those institutions to protect the confidentiality of their research participants? The ambiguous nature of the current case-by-case system of institutions choosing whether to protect research confidentiality or not, depending on the specifics of the case, reflects neither the principles of academic freedom nor our ethical responsibilities towards research participants, as outlined both by the TCPS 2 and the ethical guidelines of numerous professional disciplines. Thus, a closer examination of institutional policies and attitudes regarding researcher indemnification and confidentiality protections is warranted. This thesis set out to do exactly that.
Chapter 2. Methods

2.1. Research Methods

This research employed a mixed method design to gather both qualitative and quantitative data regarding institutional policies and practices related to the protection of research participant confidentiality. The data for this project were collected through a national survey of REB chairs, a role that is consistent across the country wherever there are projects to review by REBs with hopes of receiving federal funding for these endeavors. Although the role of the REB is to implement policy rather than to create it, we believed these individuals were most likely to be aware of internal policies regarding researcher indemnification, and thus were the best persons to approach. Accordingly, it was these individuals who were selected as prospective participants. A sampling frame of prospective institutions was created by first accessing the websites for each of the granting agencies (SSHRC, CIHR and NSERC) to determine those institutions who had entered an Agreement with one or more of the granting agencies. This resulted in a list of 272 unique institutions with funding from at least one of the three agencies, with many institutions, particularly larger ones, having Agreements with more than one. Francophone institutions were removed from the sampling frame to avoid language barriers in correspondence.

The next step involved finding the names and contact information of the REB chair or chairs (in the event of multiple REBs within the same institution, or shared chairing responsibilities) within each institution. In most cases, this was a fairly simple task, as many institutions feature their REB membership and contact information prominently on the institution’s website. In a surprising number of cases, however, this information was not easily obtained. In those cases, Internet searches were conducted using keywords including the institution’s name+REB chair+email, which sometimes provided the information from alternative online sources. If we were still unsuccessful at that point, an email was sent to the offices of the REB, or administration (usually the VP-Research) containing a request for the contact information of the REB chair or chairs. Non-respondents were contacted up to two additional times, or, requests were directed to someone else within the institution. This left a sampling frame of 207 REB chairs (or nearest contact) in 161 different English language institutions.
Personalized emails were sent to each REB chair, including a participant information sheet (see Appendix A), inviting him or her to participate in a survey through individual participant-specific survey links. Preliminary contacts also were told they could send the invitation and link to anyone else in the institution they felt might be more knowledgeable about the issues or a more appropriate respondent, and some did so. Participant-specific links provided respondents an opportunity to log out of the survey and log back in later. Those who did not respond to the first invitation were sent one additional reminder email after a waiting period of ten days to maximize the sample. The online survey was constructed and hosted on a private server by research and consulting firm SQi, which employs end-to-end survey encryption, (the same standard employed by Statistics Canada in its online surveys). The "basic" survey was brief (see Appendix B) in the hopes of collecting relevant data without burdening participants with an unnecessarily long time commitment, but space was also provided for participants to explain themselves more fully if they wished.

The survey began with demographic questions to aid in the description of the final sample. Further lines of questioning included: whether the respondent’s institution had created a researcher indemnification policy as outlined in the TCPS 2; what stage of policy development (if any) the respondent’s institution was at; what impediments to policy creation exist; what current research proposals they had seen within their institutions; and whether the respondents would favour statute-based research confidentiality protections. In addition to the survey, Internet searches also were made in attempts to locate any indemnification policies that may exist. Both the policies that were found publicly available through our independent searches, and those provided by the survey participants, were used in the analysis. The survey remained live for two weeks and 73 participants from 63 different institutions completed the survey, i.e., a response rate of 35% of prospective participants representing 39% of prospective institutions. Quantitative data was analyzed using SPSS software, and the qualitative data was analyzed using NVivo.

2.2. Ethics

This project was submitted for ethics review at SFU, categorized as minimal risk, and approved. The informed consent letter identified both the Principal Investigator (Ted Palys) and the Student Collaborator (Aaren Ivers), and provided the contact information
for SFU’s Office of Research Ethics (ORE) should prospective participants have further questions. Respondents were advised their survey responses would be aggregated with data from other participants and potentially used in articles, presentations, workshops, and this thesis. Participants were not offered any form of remuneration for their participation. Agreement to participate and an understanding of the informed consent statement was considered implicit when the respondent clicked the submit button at the end of the survey.

The main ethical concern within this project was the protection of the confidentiality of responses. While a promise of complete confidentiality was inappropriate given the limitations imposed by technology, the information we gathered was unlikely to be sought by any third-party, and the research design of this project and the technological apparatus used were implemented to protect confidentiality to the fullest extent possible. To reduce even further the chances that a third-party could gain access to the data, all information from the self-administered questionnaire that was stored in the relational databases was physically removed (flushed) daily, encrypted and transferred to an external flash or hard drive. This flushing process simply involved saving the data from the relational database to an external drive and deleting all stored responses from the relational database. All data collected for this project were stored in an encrypted container using VeraCrypt encryption software. Participants were advised that neither they, nor their institutions, would be identified without their permission. Any anecdotal comments that had the potential to identify participants were excluded, and the list of participating institutions and respondents remained confidential. Only authorized members of the research team had access to the raw data.
Chapter 3. Results

3.1. Sample Characteristics

We anticipated that most research institutions would fall into one of four categories: (1) a university or college that offers degrees up to and including the PhD, that has a medical school associated with it; (2) a university or college that offers degrees up to, and including the PhD, without a medical school associated with it; (3) a university or college that does not offer diplomas or degrees beyond the BA level; and (4) a hospital, health services institution, or independent medical school. We also included an "other" category. Table 3-1 shows the numbers of each type of institution.

Table 3-1 Types of Research Institutions Participating in the Survey

<table>
<thead>
<tr>
<th>Type of Institution</th>
<th>Frequency</th>
<th>Proportion of Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>University or college up to the BA level</td>
<td>26</td>
<td>35.6%</td>
</tr>
<tr>
<td>PhD granting institution with a medical school</td>
<td>20</td>
<td>27.4%</td>
</tr>
<tr>
<td>PhD granting institution</td>
<td>10</td>
<td>13.7%</td>
</tr>
<tr>
<td>Hospital or medical school</td>
<td>9</td>
<td>12.3%</td>
</tr>
<tr>
<td>Another type of post-secondary institution</td>
<td>8</td>
<td>11.0%</td>
</tr>
<tr>
<td>Total</td>
<td>73</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Institutions were further categorized by size based on the approximate total number of students (where applicable). The smallest institutions were those with fewer than 5,000 students; medium-sized institutions were categorized as those with more than 5,000, but fewer than 25,000 students; and large institutions were those with over 25,000 students. Across the entire sample 20 (27.4%) respondents were from small institutions, 25 (34.2%) were from medium sized institutions, 20 (27.4%) were from large institutions, and 8 (11%) respondents were from institutions with no student body.

Table 3-2 reveals the respondents in our sample are representative of all major Canadian regions: Ontario, the Prairies, British Columbia, the Maritimes, Quebec, and the North. The distribution of participants across regions is similar to what we see in the population, thus the sample provided adequate regional coverage. Most respondents, 60
(82.2%), were REB chairs, while 10 (13.7%) were staff members within the research ethics offices, and 3 (4.1%) were senior administrators.

**Table 3-2  Regional Survey Participation**

<table>
<thead>
<tr>
<th>Region</th>
<th>Proportion of Population (n)</th>
<th>Proportion of Sample (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ontario</td>
<td>44.0% (n=91)</td>
<td>39.7% (n=29)</td>
</tr>
<tr>
<td>Prairies</td>
<td>21.7% (n=45)</td>
<td>27.4% (n=20)</td>
</tr>
<tr>
<td>British Columbia</td>
<td>17.4% (n=36)</td>
<td>17.8% (n=13)</td>
</tr>
<tr>
<td>Maritimes</td>
<td>10.6% (n=22)</td>
<td>6.8% (n=5)</td>
</tr>
<tr>
<td>Quebec</td>
<td>4.8% (n=10)</td>
<td>5.5% (n=4)</td>
</tr>
<tr>
<td>The North</td>
<td>1.4% (n=3)</td>
<td>2.7% (n=2)</td>
</tr>
<tr>
<td>Total</td>
<td>100.0% (n=207)</td>
<td>100.0% (n=73)</td>
</tr>
</tbody>
</table>

All respondents were asked which of the three granting agencies (or combination thereof), they had Agreements with. Table 3-3 shows the number of respondent institutions with Agreements with each granting agency.³

**Table 3-3  Agreements with Granting Agencies**

<table>
<thead>
<tr>
<th>Granting Agency</th>
<th>Frequency</th>
<th>Proportion of Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSERC</td>
<td>60</td>
<td>82.2%</td>
</tr>
<tr>
<td>SSHRC</td>
<td>60</td>
<td>82.2%</td>
</tr>
<tr>
<td>CIHR</td>
<td>50</td>
<td>68.5%</td>
</tr>
<tr>
<td>Unsure</td>
<td>8</td>
<td>11.0%</td>
</tr>
</tbody>
</table>

To get an understanding of the areas of research carried out within each of the participating institutions – and to determine whether institutions were reviewing proposals where prospective research participants might be at risk unless confidentiality was secure – respondents were given a list of ten areas of research and asked to indicate all of the categories they had reviewed for ethics approval over the past year. This list was taken from the various areas of research identified by the National Institute of Health who administer Certificates of Confidentiality in the United States, describing areas of research in which confidentiality typically is crucial and thereby deserving of

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³ The total number is greater than the number of participating institutions because most institutions had Agreements with more than one granting agency.
extra protection. Table 3-4 shows the number of institutions stating they had seen at least one proposal in each category over the last year.

### Table 3-4 Types of Proposals Seen in the Last Year in which Confidentiality is Important

<table>
<thead>
<tr>
<th>Types of Proposals</th>
<th>Frequency</th>
<th>Proportion of Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identifiable information related to a participant’s psychological well-being and mental health</td>
<td>49</td>
<td>72.1%</td>
</tr>
<tr>
<td>Identifiable information that might lead to social stigmatization or discrimination</td>
<td>48</td>
<td>70.6%</td>
</tr>
<tr>
<td>Identifiable information regarding sexual attitudes, preferences or practices</td>
<td>36</td>
<td>52.9%</td>
</tr>
<tr>
<td>Identifiable information regarding the use of drugs, alcohol, and other addictions</td>
<td>35</td>
<td>51.5%</td>
</tr>
<tr>
<td>Identifiable information that could be damaging to financial standing, employability, or reputation</td>
<td>34</td>
<td>50.0%</td>
</tr>
<tr>
<td>Identifiable data in the context of a clinical trial</td>
<td>22</td>
<td>34.4%</td>
</tr>
<tr>
<td>Identifiable information regarding illegal conduct</td>
<td>22</td>
<td>32.4%</td>
</tr>
<tr>
<td>Proposals including genetic information</td>
<td>21</td>
<td>30.9%</td>
</tr>
<tr>
<td>Identifiable information in the context of epidemiological studies</td>
<td>19</td>
<td>27.9%</td>
</tr>
<tr>
<td>Identifiable information regarding the existence of risk factors associated with HIV, AIDS, or other STDs</td>
<td>16</td>
<td>23.5%</td>
</tr>
<tr>
<td>Unsure of what proposals have been seen in the last year</td>
<td>6</td>
<td>9.0%</td>
</tr>
</tbody>
</table>

The mean number of sensitive areas participating REBs reviewed was 4.87, with a range from 1-10, indicating that every single respondent institution was reviewing at least one category of proposals in which confidentiality was crucial and thereby requiring protection. Not surprisingly, as Table 3-5 below reveals, smaller institutions tended to see fewer types of research proposals, while larger institutions saw more, with even the smallest institutions seeing several categories of sensitive research on average.
Table 3-5  Total Number of Sensitive Areas the REB Deals with Across Institution Size

<table>
<thead>
<tr>
<th>Total Approximate Number of Students that Attend the Institution</th>
<th>Mean</th>
<th>Frequency</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fewer than 5,000 students</td>
<td>3.38</td>
<td>16</td>
<td>1.746</td>
</tr>
<tr>
<td>More than 5K but less than 25K students</td>
<td>4.47</td>
<td>19</td>
<td>2.611</td>
</tr>
<tr>
<td>More than 25,000 students</td>
<td>6.47</td>
<td>19</td>
<td>3.221</td>
</tr>
<tr>
<td>No student body</td>
<td>5.00</td>
<td>8</td>
<td>2.878</td>
</tr>
<tr>
<td>Total</td>
<td>4.87</td>
<td>62</td>
<td>2.866</td>
</tr>
</tbody>
</table>

3.2. Policy Pervasiveness

The initial question this research addressed was whether Canadian institutions that engage in research were following the directive of TCPS 2 in creating specific policies to support their researchers should third-parties attempt to procure confidential data through the threat or force of law. As stated by PRE, “Institutions under whose auspices or within whose jurisdiction such research is being conducted should establish a policy that explains how it will fulfill its responsibilities to support its researchers” (PRE, 2015, “Privacy and confidentiality”). Table 3-6 shows participant responses to the question, “Has your institution developed such a policy?”

Table 3-6  Current State of Confidentiality Policies

<table>
<thead>
<tr>
<th>Response</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>5</td>
<td>6.8%</td>
</tr>
<tr>
<td>Not yet, but are doing so now</td>
<td>17</td>
<td>23.3%</td>
</tr>
<tr>
<td>We tried, but abandoned the process</td>
<td>6</td>
<td>8.2%</td>
</tr>
<tr>
<td>No, we have yet to begin</td>
<td>41</td>
<td>56.2%</td>
</tr>
<tr>
<td>I don’t know</td>
<td>4</td>
<td>5.5%</td>
</tr>
<tr>
<td>Total</td>
<td>73</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

3.2.1. Claims of Having a Researcher Indemnification Policy

Table 3-6 reveals that the most common state of affairs is for institutions to not have a policy – the vast majority of institutions (n = 64 or 87.7%) had not even considered the process, had tried but abandoned it, or were just beginning to think about how to proceed. Even that may be an underestimate. When we look more closely at those five institutions that reported having a policy, it appeared some of those five did
not have policies that met the criteria set out in the TCPS 2, which requires a complete explanation of the nature of support an institution is willing to offer, a means to determine the level of support in individual cases, and the source of the funding for legal fees (PRE, 2015).

Of those five claiming to have indemnification policies, four of the respondents were from PhD granting institutions with medical schools, and the remainder was from another type of post-secondary institution. Some provided the policies in question and some did not. The policies submitted did address research confidentiality, but failed to meet the criteria. In one case, the policy simply stated that the researchers themselves should identify resources to help them resist disclosure (such as legal counsel and institutional support) when attempts were made through legal means to obtain confidential information. Another policy suggested legal support might be provided by the institution, but that the institution would make that determination on a case-by-case basis. Another did not include any mention of researcher indemnification within their institution in the case of third-party attempts to obtain confidential data through legal means, and further stated that personal information could be disseminated if “authorized and/or required by law or regulatory authority or enactment.” For those that did not provide the policy which they claimed included researcher indemnification, Internet searches were made to locate the policies, but none were found. Of these policies that were located, none made any mention of the responsibility of the institution to indemnify researchers nor did they indicate how the institution would support their researchers in any manner.

We did, however, find one policy online that most closely complied with the standards set out in TCPS 2, and addressed most of the concerns more explicitly than those offered by the previous respondents, presenting both the nature and the scope of the support they will offer researchers. McGill University’s (2015) Statement Concerning Institutional Support to Researchers in Maintaining Promises of Confidentiality (see Appendix C) empowers a composite body of REB members, administrators and legal

4We became aware of this policy through our independent online searches. This policy is publicly available at:
advisers – the Advisory Council on Human Research Ethics (ACHRE), to determine and offer:

Advice on the extent of promises of confidentiality made to participants in accordance with the approval granted by the REB; Investigation of and advice on current best practices bearing on the matter; Advice on whether to seek the support of professional organisations to which the researcher belongs whenever ethical obligations may also derive from one’s professional obligations; Support in attempting to resolve the dispute with the third-party seeking disclosure of participant information; Legal action or legal support to oppose third-party action to compel disclosure of confidential participant information (subpoenas, search warrants, requests for access to documents, etc.).

The document also states that the university will provide researchers with independent counsel, explaining “The purpose of the mandate will not be to provide advice on the potential consequences of the researcher’s decision on the University itself or on other parties” (McGill, 2015, p. 1). This implies that counsel will be looking out for the best interests of the researcher (and in effect, the research participants), not the reputation or financial considerations of the institution. The policy further states that assistance provided by ACHRE and the Department of Legal Services is free to researchers, and the costs of outside legal counsel will also be covered by the university. This brings the count of Canadian institutions with a researcher indemnification policy protecting all researchers within that institution with a clear indication of how they will do so, to one. To ensure our interpretation of this policy was correct – that its focus is on how researchers and their participants are best supported and not whether they will be – we confirmed our understanding with McGill’s Research Ethic’s Office (Institutional Review Board).

3.2.2. Currently Working on Policy Development

As shown in Table 3-7, respondents who selected this option were most often from large institutions followed by medium sized institutions, small institutions, and institutions that had no student body. This indicates that the larger the institution, the more likely that some attempt to create a policy is underway.
Table 3-7  Currently Working on Policy Development Across Institution Size

<table>
<thead>
<tr>
<th>Total Approximate Number of Students that Attend the Institution</th>
<th>Frequency</th>
<th>Proportion Within Institution Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>25,000 students or more</td>
<td>7</td>
<td>41.2%</td>
</tr>
<tr>
<td>More than 5K but fewer than 25K students</td>
<td>6</td>
<td>35.3%</td>
</tr>
<tr>
<td>Fewer than 5,000 students</td>
<td>2</td>
<td>11.8%</td>
</tr>
<tr>
<td>No student body</td>
<td>2</td>
<td>11.8%</td>
</tr>
<tr>
<td>Total</td>
<td>17</td>
<td>23.3%</td>
</tr>
</tbody>
</table>

Table 3-8 shows it is PhD granting institutions with medical schools which most often self-categorize as in the process of policy development. Institutions with Agreements with SSHRC and NSERC were equally represented within those in the midst of the policy development process (both n=15, or 25% of SSHRC and NSCER Agreement holders), slightly ahead of those with Agreements with CIHR (n=12, or 24% of CIHR Agreement holders). Among institutions still working on the policy creation process, the most common types of research proposals that had been seen over the last year were those that included information regarding mental health (n=11; 64.7%), proposals that included stigmatizing information (n=11; 64.7%), and proposals that included information that could damage the employment or reputation of participants (n=11; 64.7%).

Table 3-8  Types of Institutions Currently Working on Policy Development

<table>
<thead>
<tr>
<th>Institution</th>
<th>Frequency</th>
<th>Proportion Within Institution Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>PhD granting university with medical school</td>
<td>8</td>
<td>40.0%</td>
</tr>
<tr>
<td>Hospital or medical school</td>
<td>2</td>
<td>22.2%</td>
</tr>
<tr>
<td>PhD granting university</td>
<td>2</td>
<td>20.0%</td>
</tr>
<tr>
<td>University or college granting degrees to the BA level</td>
<td>4</td>
<td>15.4%</td>
</tr>
<tr>
<td>Another type of post-secondary institution</td>
<td>1</td>
<td>12.5%</td>
</tr>
<tr>
<td>Total</td>
<td>17</td>
<td>23.3%</td>
</tr>
</tbody>
</table>

Respondents who said they were currently engaged in policy development were a diverse group that ranged from simply starting to think about it to actively developing drafts, as reflected in their supplementary open-ended responses. Respondent 8, an REB chair from a large PhD granting institution stated, “I do know that discussions have taken place but I do not know how much progress has been made to date.” Respondent 39, an REB chair from the same type of institution, but with a small student body stated,
“We are in the process of exploring what a policy may include.” Likely this ‘exploration’ would include some initial research regarding the requirements in the TCPS 2 and general discussion, but it is not clear what else may be included beyond that. Respondent 29, an REB chair from a medium sized BA granting institution simply stated, “We are in the very early phases of getting organized to write this policy.” A slightly more specific statement was made by Respondent 63, the REB chair of another type of post-secondary institution, with a small student body who stated, “Bits and pieces are there but more work is ongoing,” suggesting there was a partial policy written addressing some of the suggestions of the TCPS 2 regarding researcher indemnification.

Table 3-9 shows who is involved in policy development across the institutions that indicated they were currently in the process of creating a researcher indemnification policy.

Table 3-9    Individuals Involved in the Policy Development Process

<table>
<thead>
<tr>
<th>Individuals Involved</th>
<th>Frequency</th>
<th>Proportion Within Individuals Involved</th>
</tr>
</thead>
<tbody>
<tr>
<td>REB Members</td>
<td>12</td>
<td>70.6%</td>
</tr>
<tr>
<td>Staff Members</td>
<td>11</td>
<td>64.7%</td>
</tr>
<tr>
<td>Legal Advisors</td>
<td>10</td>
<td>58.8%</td>
</tr>
<tr>
<td>Senior Admin.</td>
<td>10</td>
<td>58.8%</td>
</tr>
<tr>
<td>Researchers</td>
<td>6</td>
<td>35.2%</td>
</tr>
<tr>
<td>Faculty Association or Union</td>
<td>5</td>
<td>29.4%</td>
</tr>
</tbody>
</table>

Among the 17 institutions whose respondents stated they were in the midst of creating a policy, 12 (70.6%) stated that REB members were involved in policy creation, followed by staff members, legal advisors, senior administrators, researchers and faculty associations or unions. This is concerning, because the TCPS 2 states “the institution should establish such a policy in collaboration with its researchers” (Panel on Research Ethics, 2015, “Privacy and confidentiality”). It appears the very group of people the TCPS 2 directs to be a part of policy creation are not being engaged in the development process. A possible explanation for this is that REB members have a range of backgrounds, including research, and respondents may have simply categorized these individuals as REB members, however, this conundrum still invites discussion. A further question that presents itself is how the heavy saturation of administrative representation involved in policy development balance their involvement with provisions to avoid...
institutional conflict of interest – or has this even been considered? In addition, while REB members may certainly have insight into policy development, what assurances are there that they are operating independently of administration?

3.3. Impediments to Policy Creation

When examining the policy creation impediments offered by respondents, there were some significant issues that were found across institutions regardless of what stage of policy creation an institution was at. Respondent 4, an REB chair from a medium sized PhD granting institution surmised, “I am pretty sure that you will find that there is very little appetite to develop such a policy at the university level.” This assumption seems to be supported by the data, but why is this the case? Table 3-10 shows the survey results indicating what impediments to policy creation respondents selected; these included both reasons for abandoning the process, and reasons given for not yet starting policy development.

Table 3-10  Impediments to Policy Creation

<table>
<thead>
<tr>
<th>Impediment</th>
<th>Proportion Within Begun but Abandoned (n=6)</th>
<th>Proportion Within Yet to Begin (n=41)</th>
<th>Proportion Within Entire Sample (n=73)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unaware the requirement existed</td>
<td>0</td>
<td>20 (48.8%)</td>
<td>20 (27.4%)</td>
</tr>
<tr>
<td>Unclear who would be involved</td>
<td>0</td>
<td>13 (31.7%)</td>
<td>13 (17.8%)</td>
</tr>
<tr>
<td>Rare event, thus not a priority</td>
<td>1 (16.7%)</td>
<td>6 (14.6%)</td>
<td>7 (9.6%)</td>
</tr>
<tr>
<td>Administration not receptive</td>
<td>4 (66.7%)</td>
<td>1 (2.4%)</td>
<td>5 (6.8%)</td>
</tr>
<tr>
<td>Still figuring out what a policy should look like</td>
<td>2 (33.3%)</td>
<td>0</td>
<td>2 (2.7%)</td>
</tr>
</tbody>
</table>

As seen in Table 3-10, there are some impediments that apply to both those that abandoned the process and those that had yet to begin policy creation, however each of these groups seemed to have faced distinct issues that impeded policy development. An unreceptive administration was described as the greatest impediment by those who had abandoned the process, but was less of an issue for those that have yet to begin. For the latter group, the key issues they offered were being unaware of the requirement, and being unclear about who should be involved in the process. The open-ended survey

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5 The percentages add to more than 100 because people could cite multiple categories.
responses not only gave insight into these issues, but also uncovered additional impediments, which are discussed below.

3.3.1. Unreceptive Administrations

When assessing both the qualitative and quantitative data, an unreceptive administration was found to be one of the key issues hindering policy development within the sample. Among respondents from the six institutions that admitted they had attempted to create a policy but abandoned the process, 4 (66.7%) of them stated it was because administration was not receptive. Respondent 37, an REB chair from a medium sized PhD granting institution summarized, “My understanding is that this was discussed by the administration, was deferred pending consultation with other institutions in the province and I’ve heard nothing since. My conjecture is that it is of low priority and hasn’t been pursued.” Respondent 47, an REB chair of a medium sized PhD granting university stated “The REB brought the relevant Article to the attention of the Dean of the Faculty of Graduate Studies and Research a few years ago. I’m not sure if any progress has been made since then.” Respondent 8, an REB chair from a large PhD granting university made similar claims: “Institutions appear very slow/unwilling to draft straightforward policy that includes all researchers (faculty and graduate students).” An unreceptive administration was often cited as a source of difficulty in making progress in policy creation, and one respondent suggested that this lack of receptivity was tied to the tendency of administrations to avoid bad publicity and negative public opinion:

Though rare, cases where there are threats to research confidentiality have not been handled well by university and college administrations, which have not supported their researchers adequately. Administrations are also evidently in a conflict, given their desires to avoid the bad publicity over ‘supporting’ protection of confidentiality of individuals who may be engaged in illegal or socially disreputable activity. (Respondent 14, REB chair of a small BA granting institution)

The preceding comment acknowledges the tendency of administrations to distance themselves from controversial, yet important areas of research when legal issues loom. These are exactly the circumstances under which SFU and U of O administrators distanced themselves from Ogden, and Bruckert and Parent. At present, it seems that though some administrations have been made aware of their responsibilities, university reputation and public opinion trumps the fundamentals of ethics and the protection of research confidentiality, especially when the research is
centred on anything remotely controversial. Of course, there are other reasons why administrations might not be receptive to policy development, but institutional image undoubtedly plays a large part.

### 3.3.2. Unaware the Directive Existed

As seen in Table 3-10, among the 41 institutions that had yet to even consider creating such a policy, 20 (48.8%) stated that were unaware this directive existed. Respondent 69, an REB chair from a small BA granting institution stated “We are quite a small university; relatively young. I’d suggest we’re just a little behind in thinking some of this through.” Respondent 43, an REB chair from a medium sized post-secondary institution that is not a college or university made a similar statement, saying they were “just becoming aware this can be an important issue.” Respondent 55, from a large PhD granting institution with a medical school stated, “I chair one of the REBs and I don’t think that we have discussed this issue.” In consideration of the fact that over half of the respondents offered they had no policies because they did not know the directive existed, perhaps simply initiating the conversation is progress. It is concerning that 20 (27.4% of the entire sample) respondents stated they were unaware of the directive to have a researcher indemnification policy under the TCPS 2. This is a significant proportion, which indicates a need for REBs to become better acquainted with the guidelines of the granting agencies in order to protect those that participate in their institutions’ research. The requirement for researcher indemnification is not an obscure detail buried in the depths of policy and marginally publicised; a discussion panel featuring the very issue of protecting research confidences from legal requests was explored in a panel at the Canadian Association of Research Ethics Boards (CAREB) 2017 Halifax conference, and is certainly something that all REB members should be cognizant of.

### 3.3.3. Not a Priority

Among those yet to begin the policy development process, 6 (14.6%) stated that requests for information by third-parties were a rare event, thus not a priority. Indemnification policies seemed to be a low priority for various reasons across different institutions. The following statement suggests that this respondent’s administration may be willing to move forward on a policy, provided it fits into their schedule:
We have considered it and talked about it at the REB. However, it has not yet been taken to administration for consideration - but we hope to, in the next calendar year. The timing has simply been difficult in terms of making this a priority for administration. (Respondent 49, REB chair of a health services or medical services institution with no student body)

Stalled policy development due to its lack of being an institutional priority is not a discrete category, and is intrinsically tied to the receptiveness of an institution’s administration. The question becomes, how to encourage administrators to make it a priority? Institutional priorities tend to be set by those at the top – if administrators make clear that protecting research confidentiality from legal requests is important within their institutions, the matter will likely be taken more seriously and be prioritized accordingly.

There were also those that eschewed the notion that policy creation should be relegated to low priority status, offering this counterargument:

Having an emergency preparedness plan is something that communities and universities have, such as evacuation routes or strategies for campus lockdowns when there is a shooter, etc. In the research community, a similar need is there that needs to be addressed. Coming up with an emergency response plan on the fly -- when the crisis is unfolding before you -- is the least effective way to make decisions and protect people. Hope for the best.... plan for the worst. (Respondent 64, REB office staff member from a PhD granting institution with a medical school)

Respondent 64 quite fittingly describes the experiences of Ogden, Bruckert and Parent, and Bauer and Maillé, as crises. These are situations wherein a researcher’s duty to their research participants, reputation, character, and financial standing are placed in a perilous position. Researchers should feel that upholding their obligations of confidentiality to their research participants is an endeavor that their institutions value and prioritize accordingly – not endure the stress, uncertainty, and possible financial responsibility of dealing with such instances with no support from their administrations. These are exactly the circumstances where researchers need the aid of their institutions, not when administrations should attempt to distance themselves from controversy.
3.3.4. Lack of Guidance and an Understanding of What an Indemnification Policy Should Include

Among the six respondents that stated they had begun, but abandoned policy creation, 2 (33.3%) stated they were still trying to figure out what such a policy might look like. Lack of guidance and understanding of what to include in an indemnification policy was expressed across different levels of policy development by other respondents as well. One respondent suggested a working group be assembled by the Secretariat to create an outline of the requirements an indemnification policy would encompass to meet the needs of researchers and research participants should a third-party attempt to obtain confidential information through the threat or force of law:

Rather than have a range of individually worked out arrangements, which may not fulfil everyone's obligations, it would make sense for the Secretariat to create a guidance for supporting researchers, in consultation with stakeholders, that each administration would be expected to live up to. (Respondent 14, REB Chair of a medium sized BA granting institution)

A second respondent made similar claims:

A basic policy would provide clarity and a set of generally understood principles that would presumably be more efficient and over time, reduce legal costs for both universities and the courts; it would not preclude additional policies on the part of the universities. (Respondent 52, REB chair of a medium sized alternative post-secondary institution)

These comments suggest that some form of policy template, provided by the Secretariat or PRE, would give individual institutions a clear outline to facilitate the policy creation process. However, as the latter comment suggests, it would be sensible to allow institutions to create additional policies to meet their needs in order to maintain autonomy. The idea of “boilerplate” policies was mentioned by an REB chair of a large medical institution, who used similar methods by providing Principal Investigators with a range of REB applications that needed to only be moderately customized by researchers. This respondent stated that they had found this to be very helpful for researchers seeking REB approval, and aided them in avoiding wasting time on proposals that would never be approved. A similar “boilerplate” method, if initiated by PRE or the Secretariat, would help many institutions who want to begin policy development, but are unsure as to where to begin.
In addition, many respondents were very clear that they were currently unable to tackle policy creation as they saw the issue as overly complex and beyond the expertise available within their institutions. This was illustrated by Respondent 32, an REB chair from a medium sized PhD granting institution affiliated with a medical school who stated, “Other than the current REB Chair, who is a trained lawyer (non-practitioner), the REB itself and probably the Office of Research Services, currently lacks the expertise to craft such a policy.” Respondent 63, an REB chair from a small post-secondary institution that is not a college or university made similar claims, offering “The legal details of such policies often extends well beyond the expertise of REB members.” Not surprisingly, Respondent 68, an REB chair from a small institution that grants degrees up to the BA level stated “As a small institution, this issue has not come to our attention before. Our REB is also new and lacks extensive experience.” Creating a policy would require specialized skills: a comprehensive knowledge of Canadian law, an understanding of the professional guidelines within several disciplines (the fields of health and social services have exclusionary rules for confidentiality in some circumstances), knowledge of both scientific and social science research, familiarity with the TCPS 2, and a background in ethics. While such individuals undoubtedly exist within various institutions across Canada, it is unlikely such individuals exist in all research institutions.

### 3.3.5. Unclear Who Should Be Involved

Among those yet to begin the policy creation process, 13 (31.7%) claimed it was unclear who within their institution would be involved. Many respondents expressed a lack of clarity regarding whose responsibility it was to create indemnification policies within their institution:

> I believe one of the reasons that we don't have policies happening at the institutional level is that research ethics matters tend to get quickly shuffled over to the REB offices because it dealt with the TCPS. Establishing an institutional policy has to happen at the institutional level. In effect, no one 'owns' this issue at the institution. REBs can be the 'squeaky wheel' that keep reminding the key institutional players but the REBs don't have the authority to make this policy on their own. (Respondent 64, REB chair of PhD granting institution with a medical school)

This is a significant impediment to policy creation. If no one takes ownership of the task, obviously there is no chance of moving forward. Respondent 16, an REB chair of a
hospital or medical school stated, “This would be an institutional/research institute policy rather than an REB policy,” which is correct. Certainly, no legitimate policy can be implemented at any institution without some involvement of its administration; REB members themselves can help craft a policy, but it is up to the administrators to make sure it is implemented across the institution, which leads us back to the initial problems of unreceptive administrations and policy development being of low priority.

3.3.6. The Minimal Risk Research Justification

The areas of research different institutions engaged in appeared related to the attitudes some had regarding indemnification policies to protect research confidentiality. Some respondents cited the fact that their institutions focus on minimal risk research as the reasoning behind their lack of urgency in policy development. They believe that because they do not engage in research in areas traditionally considered sensitive in nature, such as those including information on illegal conduct, that the likelihood of threats to confidentiality would be miniscule. Respondent 3, an REB chair from a small institution offering degrees up to the BA level stated it was "not a high priority due to the nature of research that our REB sees (which are almost exclusively low / minimal risk).” Respondent 50, an REB chair from a medium sized institution, also offering degrees up to the BA level echoed a similar sentiment stating, “We will be checking how supportive college administration is, but most of our research here is minimal risk.” However, others did not share the belief that a preponderance of minimal risk research made the issue any less urgent:

There are several areas of research that heighten sensitivity of researchers, REBs, and participants to conditions under which assurances of confidentiality would require careful consideration. However, the [Maillé] case in Quebec right now involving the wind farm research is a critical example of a situation in which there may have been no foreseeable reason why the data would be used in a legal action. That case is not likely to be an isolated event as it will also draw attention of members of the legal establishment to consider requesting researcher’s data when it is relevant to a case. (Respondent 73 – REB chair from medium sized institution which grants PhDs and is affiliated with a medical school)

Community colleges have historically focused on teaching over research. However, many respondents from colleges reported that their institutions were pushing faculty to increase engagement in research. Despite being newcomers in the field of
research, some small and medium sized institutions realize that though they may not currently focus on research considered high risk, they are mindful of their new roles. Respondent 41, an REB chair from an institution granting degrees up to the BA level stated, “As a small community college we are unlikely to do such research, however as we expand and as our degree offerings expand, we will be developing policy on an ongoing basis.” Respondent 50, an REB chair from a medium sized BA granting institution stated, “We are a teaching based college with some faculty doing research…more and more research is being conducted every year so developing a firm policy would be beneficial.”

3.3.7. Staff Turnover

A further issue that seems to be hindering the policy creation process across institutions is staff turnover. Staff turnover was not included in the list of policy development impediments offered respondents, but was repeatedly referenced when respondents answered open-ended questions. Respondent 59, an REB chair from a small institution granting degrees up to the BA level stated, “There has been a recent change to the chair of the REB and several new members have been added to the REB; thus we are currently in a time of transition.”  Respondent 57, an REB chair of a hospital or medical school affiliated with a university made a similar statement: “We have had many changes in REB staff/administration and structure. Policy meeting is scheduled…and this is something on the agenda.” Acknowledging this phenomenon, one respondent stated they needed to continue to move forward with policy creation, despite staffing issues:

Such a policy has been discussed, but it was not a priority for researchers or administration in light of low volume of funded research. [Our institution] has been poised to develop and advance its research agenda on several occasions, but each time the administrator overseeing research has left. We are starting again now: new MOUs with SSHRC and NSERC, new keen faculty -- so we want to stay on top of this. (Respondent 18, REB chair of an institution granting degrees up to the BA level)

3.3.8. Do Not Have the Time to Dedicate to Such a Task

Another hindrance to policy creation mentioned by respondents was the considerable amount of time that would be required to create such a policy. Respondent
6, a staff member from the REB office at a large PhD granting institution stated, “I know we need one, but due to under staffing, I am unable to find time to even begin.” While some respondents were aware of the directive to create policies within their institutions, it may require those in charge of policy creation to make the time, or hire additional staff. Several respondents made mention of their belief that they were already facing more work than time to accomplish it. This sentiment seemed particularly strong among smaller institutions that had just recently increased their emphasis on research, and were finding themselves in additional positions pertaining to research with little or no compensation outside of the positions they were originally hired for.

### 3.3.9. Financial Cost

The smaller the institution, the less likely they were to have begun planning a policy. As can be seen in Table 3-11, nearly half of respondents who selected that they have yet to consider such a policy were from small institutions, followed by medium institutions, institutions with no student body, and large institutions.

<table>
<thead>
<tr>
<th>Total Approximate Number of Students that Attend the Institution</th>
<th>Proportion of Those Yet to Begin Policy Development</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fewer than 5,000 students</td>
<td>17 (41.5%)</td>
</tr>
<tr>
<td>More than 5K but less than 25K students</td>
<td>15 (36.6%)</td>
</tr>
<tr>
<td>More than 25,000 students</td>
<td>3 (7.3%)</td>
</tr>
<tr>
<td>No student body</td>
<td>6 (14.6%)</td>
</tr>
<tr>
<td>Total</td>
<td>41 (100%)</td>
</tr>
</tbody>
</table>

This may be due to smaller institutions being less capable of managing the financial cost associated with supporting their researchers in a legal battle. A respondent from a small institution explained:

> In light of [our] size and budgetary constraints, it would be disastrous if we were faced with the obligation to support a researcher confronted with a legal threat to confidentiality - the moral obligation would likely exist in any event. As support for research grows, the likelihood of such a threat becomes more palpable. (Respondent 18, senior administrator from a small BA granting institution)

While the understanding of the TCPS 2 directive to create researcher indemnification policies exist in some cases, as is the understanding of the ethical duty
of the institution to support researchers, the problem is of a practical nature. How can an institution with little discretionary funding guarantee financial support that could run from thousands to hundreds of thousands of dollars (as was the case for Bruckert and Parent)? Respondent 6, a staff member from an REB office at a large PhD granting university suggested, “A national legal defense fund could be established to support researchers when institutions don’t.” The idea of pooling resources could assuage some of the trepidation of institutions due to financial insecurity. However, initiating such a fund presents several logistical problems and would require the participation of multiple institutions. Despite this, the idea of institutions implementing a collective fund was an idea that several respondents were interested in exploring further.

3.4. Navigating Research without Institutional Researcher Indemnification Policies

In the absence of policies that define exactly how an institution plans to support their researchers in the case of legal threats to research confidentiality, how are researchers and REBs currently navigating research? It appears that legal requests for confidential participant data have not gone unnoticed by the respondents in the survey, and several participants have voiced fears about the effect of this on academic freedom. What was of great concern to some respondents was the increasing possibility of compromised research confidentiality, and the effect of this on current research within their institutions. Respondent 44, an REB chair of a large PhD granting institution stated “Overall, the subpoena worry is starting to have a chilling effect on researchers.” This sentiment was echoed by Respondent 35, an REB chair in a large BA granting institution, who stated, “If researchers cannot guarantee the anonymity of participants, there is every likelihood that participants will not want to participate in future research activities, including in the social sciences.” Beyond the conjecture of these two respondents, another made it abundantly clear that if confidentiality could not be guaranteed to research participants, the research would not pass ethics review:

Our REB has only recently handled a couple of projects where it was clear this might be a highly salient issue. For the first one, we were able to confirm that the information would be unidentifiable. For the second, we are awaiting clarification from the researchers on how such potential threats to confidentiality would be handled. Unless confidentiality can somehow be assured, this project will likely not be approved for data collection at our college. (Respondent 43, REB chair
of an alternative type of post-secondary institution that is of medium size)

The idea of ceasing engagement in research on controversial topics is not something many researchers find acceptable – their jobs require them to help accumulate knowledge on important issues and feed this knowledge back to the community. Rather than sitting idly by while research into important topics that require the participation of members of the public with firsthand knowledge of social phenomena is scaled back, or engaging only in research in areas where confidentiality is not a requirement, it makes more sense to continue to promote research into areas which may include controversial topics to further policy development aimed at solving social problems. However, it would be irresponsible for institutions to encourage such research and continue to benefit from it (both financially and in reputation), without meeting their obligations under the TCPS 2 to help protect the research confidences of the very people who make that research possible.

3.4.1. Anonymizing Data As Soon as Possible

While researchers suffer the administrative inertia in regard to the lack of urgency in safeguarding research confidentiality through institutional policy, some REBs are taking what they consider to be appropriate steps to safeguard confidential data from the possibility of disclosure to third-parties. One such strategy involves removing identifiers from data, so should third-parties request confidential information, the participants’ identities would be protected:

Another thing we are now doing is to ask researchers to stay away from using written consent in these cases, and to either never learn or to destroy all identifying information as soon as possible (if it makes sense for the protocol). (Respondent 44, REB chair of a large PhD granting university)

Moving away from written participant consent in research in which the participant would not want to be identified is a sensible idea. Allowing participants to offer oral consent in its place eliminates the risk of a paper trail, yet this practice varies across institutions (as well as within institutions). Redacting identifiers at the earliest logical stage in the research process is also a good idea, although this does not guarantee confidential information will remain as such, as was discovered by Bruckert and Parent when their research assistant was able to identify Magnotta as a research participant to
police through recognizing his face from the news, and recalling his pseudonym. While
the idea of relying on oral consent has not been embraced by all institutions, it is
consistent with appropriate protocols described in the TCPS 2.

3.4.2. Designing Projects to be Defensible via the Wigmore Criteria

Another strategy being employed across Canadian institutions is ensuring
research projects are designed to meet the Wigmore criteria. Scholars Palys and
Lowman (2000) have been advocates of this practice for nearly two decades, and the
fact that all four Canadian cases thus far have invoked the criteria and done so
successfully affirms the wisdom of this practice. To be successful, it is imperative for
researchers to take all the principles of the Wigmore criteria into account before the data
collection stage. The four 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 relationship between the parties;

3. The relation must be one which in the opinion of the community ought
   to be sedulously fostered; and

4. The injury that would inure the relation by the disclosure of the
   communications must be greater than the benefit thereby gained for
   the correct disposal of litigation. (Wigmore, 1905, p. 3185; italics in the
   original)

Respondent 6, an REB staff member from a large university granting PhDs
stated, “We are aware of the Wigmore Criterion and have worked with legal council to
draft consent forms which may be defensible.” For protocols in which confidentiality is
important, it would be pragmatic for all REBs to anticipate requests for the disclosure of
confidential data, and ensure all research projects are designed accordingly. Of course,
this would require that members of REBs across Canada are aware of the Wigmore
criteria, and have an understanding of how a research project could be designed the
successfully meet the criteria. This would require not only the education of REB
members, but it would also require that researchers be willing to fight the battles. While
taking steps to meet the Wigmore criteria is laudable, this offers no financial protection
for researchers who choose to resist legal attempts by third-parties to obtain data in
relation to a costly legal battle, thus institutional support is still required to finance battles to protect research confidentiality. In addition, although the application of the Wigmore criteria has been efficacious thus far, there is no guarantee that it will always be successful, and should a researcher resist providing the information after a court rules that they have failed to meet the criteria, the researcher could end up in prison. Designing research projects to meet the Wigmore criteria may strengthen the likelihood of success when and if confidentiality is challenged, but provides no guarantee of success and does not eliminate the burdens on the researcher associated with proving in court that they meet the criteria for a research participant privilege. Such endeavors still involve a considerable time commitment, stress, and legal funding. Both anonymizing data as soon as possible and designing research projects to meet the Wigmore criteria are important, but these initiatives instituted by REBs and researchers are not enough to comprehensively protect the research confidentiality of our participants. With REBs and researchers doing their parts, it becomes apparent that it is time for administrators to fulfill their obligations as well.
Chapter 4. Discussion and Conclusion

The primary goal of this research – to discover which institutions across Canada have developed researcher indemnification policies to support their researchers in protecting research confidentiality, and uncovering how members of the research community are addressing challenges to research confidentiality – was met. By implementing a national survey of REB chairs, we engaged the right decision-makers, the survey was designed in a way that made the basic information easy to acquire, and there was room for explanations allowing for insight into why respondents answered the way they did. The survey covered the major regions in Canada, with similar representation as that which can be seen in the population of all institutions who receive federal funding from SSHRC, CIHR, and NSERC. The survey has provided an understanding of issues related to research taking place across Canadian institutions, from small community colleges in remote locations, to sprawling urban institutions with huge student populations. The types of research going on across Canada were found to include everything from information relating to psychological well-being in the social sciences, to that which includes genetic information in the hard sciences.

The literature review showed that when institutions in Canada have no clear plan in the event of legal threats to confidentiality, the results have been negative outcomes for a variety of stakeholders in the research establishment. The group with the most at stake were the research participants who were guaranteed the confidentiality of their involvement in research. Researchers who were responsible for safeguarding their participants' identities found their institutions were of little support when legal authorities attempted to obtain their participants’ confidential communications. In these instances, it was the researchers themselves who took on the burden of fighting threats to confidentiality (albeit with support from various members of the research community, but with varying nominal levels of support from their administrations). These researchers were subjected to the unsavoury choice between upholding their ethical obligations to their participants, or facing serious personal, financial, career, and legal repercussions. Ironically, institutions who did not support their researchers for fear of bad publicity, found themselves on the receiving end of negative public opinion and a lack of confidence in them by the community at large, including the granting agencies, presiding...
judges involved in the litigations, other academics, and their own researchers. In consideration of this, the suggestion of the Agencies for institutions to have policies in place is a pragmatic one; this allows researchers to make legally informed decisions as to how to respond to requests for confidential data in a timely manner with a full understanding of the legal ramifications of their responses, eliminating some of the uncertainties as to how they should proceed. The results of this project should be of concern to all of us engaged in research. Despite respondent claims of having policies that indemnify researchers, most of the policies we examined did not meet the criteria set out in the TCPS 2. Only one institution, McGill University, was found to come close to meeting all the criteria. While many institutions claimed to be somewhere along the continuum of engagement in policy development, over half of respondents, 45 (61.7%), stated they had not begun policy development, or had no idea if their institution had a policy at all.

Respondents who said that they had created policies or were somewhere along the policy development process tended to be from the larger institutions offering the most diverse programs and the highest levels of education. The individuals involved in policy creation were usually REB members, staff, legal advisors and administrators. Unreceptive administrations appeared to be the greatest impediment to policy creation reported throughout the sample. The lack of receptiveness was shown through a variety of ways, including taking suggestions to begin the policy development process under advisement, and putting them on hold indefinitely. Tied to the lack of receptiveness was the tendency to relegate such an initiative to low priority status – perhaps so low, a policy would never go beyond the discussion stage. A surprising number of respondents claimed they were unaware of the requirement to provide support in the form of indemnification to researchers, suggesting some institutions may benefit from broadening their understanding of the TCPS 2. The minimal research justification was offered by some respondents as a reason for their lack of urgency regarding policy development, however in consideration of some of the seemingly benign types of research of which confidential data has been requested through law, such as the wind farm data, this reasoning is not very compelling; as we have seen, confidential information has been sought in several circumstances, not just in matters of criminal litigation but across a variety of research areas and types of legal proceedings. Further impediments offered by respondents included problems associated with staff turnover,
lack of time to put towards policy development, and a dearth of staff with the expertise required to attempt to fully engage in policy creation. The final impediments to creation of policy offered were prohibitive costs associated with such an endeavor and a lack of understanding regarding what such a policy would include.

4.1. Addressing the Impediments to Policy Creation

With a clear understanding of what respondents described to be the major impediments to policy creation within their own institutions, there are several plausible remedies, with some being offered by the respondents themselves.

(1) Administrators, the only ones who are in the position to introduce policy on the institutional level, need to make researcher indemnification a priority. Institutions must be held accountable.

(2) Of respondents, 20 (27.4% of the entire sample) said they were unaware that the directive existed. Some REB members indicated their REBs were understaffed and lacking resources, making matters outside of approving protocols secondary. Institutions should ensure their REBs not only have an adequate amount of staff to fulfill their REB duties within the institution, but also ensure that REB staff has the time to stay abreast of policy interpretations related to the TCPS 2.

(3) The idea that only engaging in "minimal risk" research is a valid justification for not engaging in policy development is flawed. As was illustrated in the Maillé case, subpoenas can arise in relation to almost any project, including those that do not appear especially controversial or sensitive at the point they are being designed and approved.

(4) Impediments including staff lacking expertise, staff turnover, and lack of guidance in terms of what a policy should look like, could all benefit from PRE or the Secretariat creating a basic template that institutions could follow, outlining the main considerations an indemnification policy should include. Additionally or alternatively, the Secretariat might make some statement as to whether it believes the McGill policy meets the criteria PRE outlined.
To address the concerns of institutions with little discretionary funding to devote to legal costs should their researchers choose to fight to protect research confidentiality in court, a consortium of similar institutions could all pay into a fund which would protect researchers from all the institutions involved. Alternatively, smaller institutions may individually or collectively seek insurance to cover prospective legal costs, as institutions such as SFU already do.

Certainly, there is no single resolution that would bring all Canadian research institutions into compliance with the TCPS 2, but now that there is an understanding of the major stumbling blocks on the road to policy development, this information will be useful for those interested in making progress. Whether research is focused on the human body, human psychology, or the human experience, all community members who altruistically take part in our quest to add to the pool of academic knowledge deserve to have their confidentiality protected by the very institutions that are benefitting from their participation.

4.2. Limitations and Future Research

One limitation of the present study was the removal of Francophone institutions from the sampling frame. In acknowledgement that the two most recent legal requests for confidential participant information each occurred in Quebec, it is possible that Francophone institutions would have been able to provide some insight into the institutional research culture within the province. Despite this, 4 (5.6%) respondents from the sample were from Quebec. While all English-speaking institutions were invited to participate in the survey, not all did so. However, we feel the sample was adequate to draw some conclusions and get an understanding of the current state of affairs regarding institutional researcher indemnification policies in Canada. In all likelihood, those institutions who had created research indemnification policies would have opted to participate so that their investment in the issue would be acknowledged. For this reason, and because of our independent investigation, we feel that it is unlikely that we have underestimated how many policies actually exist outside our sample. An additional limitation of the study was allowing participants to self-categorize. When later comparing their self-categorizations to the qualitative data they provided, this resulted in some inconsistencies and lack of clarity. For example, many respondents placed themselves
in the process of policy development, but whether this process involved simply thinking about the matter, or whether the respondent had taken any sort of action was unclear. To address this, future research requires more in-depth investigation, including interviews, to clear up these ambiguities.

This research has shown that institutions summarily pocket research dollars from the federal granting agencies without preparing for legal requests for confidential data. While some of these demands have been foreseeable (such as data pertaining to crimes or criminality), others have not been, putting the confidentiality of any type of research where privacy is important at risk, regardless of the area of research engaged in, or the researcher’s best efforts to protect the confidentiality of their participants. Due to institutional mandates of community engagement, open access research, and knowledge mobilization, academic research is more widely available to the public than ever before. The use of academics as experts in court is also delivering the findings of academic research to a much wider audience. As research increasingly continues to be disseminated in the public sphere, the possible negative outcomes for participants whose confidential communications are revealed increase exponentially. Threats to research confidentiality in Canada have been met with researchers who have fought to protect their participants; creating policies to protect these researchers upholding the very standards that their institutions have set is not an unreasonable request.

Institutional policies that protect research confidentiality should be in place in all institutions conducting research. The threat to academic freedom is growing, and it is time that this is addressed and remedied by the research community. It is the obligation of all of us engaged in research to protect our research participants and remain trustworthy in our efforts to uphold our obligations to protect research confidentiality. Without trust, not only between researchers and participants, but also between researchers and REBs and their administrations, research is impossible.
References


Canada Evidence Act, R.S.C. 1985, c. C-5.


Center for Gender Advocacy v. Quebec, 2016 QCCS 5161


Ogdenv. Simon Fraser University, 1998 BCJ 2288


Appendix A.

Information Sheet for
National Survey Regarding Institutional Confidentiality Policies

REB File: 2016s0246
Funding Source: SSHRC Small Grant awarded to Palys
Principal Investigator: Ted Palys, PhD; Professor; email = [mask]@sfu.ca; office phone = [mask]
Student Collaborator: Aaren Ivers, MA Student; email = [mask]@sfu.ca; phone = [mask]

To Prospective Participants:
We invite you to participate in a study being conducted by Dr. Ted Palys (Professor) and Ms. Aaren Ivers (MA student) of Simon Fraser University regarding institutional policies for the provision of legal support for the defense of research confidentiality. Where such policies have been developed, we are interested in hearing what these policies entail and how they are constructed. Where they do not yet exist, we are interested in hearing what factors have impeded doing so.

We have sent you this email because your institution has an MOU with the federal government that commits it to abiding by the ethical principles embodied in the TCPS. REB Chairs at all institutions who have MOUs with one or more of the granting agencies are being asked to participate. Where institutional web sites did not identify that individual, we have sent this solicitation to whoever we thought might be best able to forward our request to that individual, or to a generic REB email address. We are approaching you directly and have not asked your institution for permission to approach you.

Basic participation in the research involves completion of an 8-item survey that can be done in 10-15 minutes and will allow us to compile a very basic profile of how broadly such policies have or have not been adopted. Most questions also provide space for a more open-ended explanation, and we do hope you will take the opportunity to elaborate. In the event you do so, completion might take a half hour or so. You will be considered to have consented to the survey if you complete it and click "submit."

There is also a question that asks whether you would be willing to be interviewed at greater length about the issues addressed in the survey; if you indicate you are amenable, you would be contacted by either Dr. Palys or Ms. Ivers via telephone or Skype and asked again about your consent at that time. Interview length will vary depending on the talkativeness of the interviewee and extent of information to be shared, but are likely to be in the range of 30 minutes to an hour each. There is no requirement to do the survey and the interview.

As you are no doubt well aware, your participation in this project is completely voluntary and your consent can be withdrawn at any time. If you were to withdraw, any identifiable data that we have from you will be destroyed. If any of your data has already been anonymized, we will not be able to destroy it because we will not have any way of identifying which is yours.

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3 The Interagency Advisory Panel on Research Ethics (PRE) has offered an interpretation of Article 5.1 of the TCPS that explains that research institutions have an obligation to provide such support and "should establish a policy that explains how they will provide that support." See point 2 at http://www.pre.ethics.gc.ca/eng/policy-politique/interpretations/privacy-privee/
This "minimal risk" project has been reviewed and approved by the SFU REB. If you have any concerns about how the project is conducted, you should address them to Dr. Jeff Toward, Director of the Office of Research Ethics at Simon Fraser University, whose contact phone is and email is @sfu.ca.

The most complex ethical issue in this research pertains to research confidentiality, for several reasons. First is that the survey is being conducted over the internet, and the interviews (if you choose also to take part in that portion) will be conducted over the telephone or Skype, and none of those media are absolutely secure. On the other hand, the information sought is not particularly sensitive, will often refer to publicly available information (e.g., policies that have been developed), and is unlikely to be of interest to legal authorities. Further, if you take part in only the "basic" survey that asks primarily for categorical responses, your data will simply be aggregated with all other respondents such that neither you nor your institution will be identifiable.

Our default practice is to protect both individual and institutional confidentiality, which we will do by following the procedures detailed below. If, however, you reveal information about the internal dynamics of your institution and/or the processes by which policies have been developed (or not) and either don't mind if you and/or your institution are identified or would prefer to be identified, then you will have an opportunity to note that during the survey. Our intention is simply to generate data that will help ensure the national dialogue on confidentiality protections proceeds on an appropriate empirical foundation. Your participation – particularly in the "basic" survey – is important to ensuring a representative and comprehensive national snapshot of views and policy developments at this time.

Beyond the above, and regardless of your confidentiality preferences, we will do the following:

- employ a secure socket layer (SSL) connection encryption standard XHTML-based form for the survey so that all information transmitted is encrypted by default
- store all information that is shared with us in a relational database
- to reduce the chances that a third party may gain access to the data, all information from completed surveys that is stored in the relational databases will be physically removed (flushed) daily, encrypted and transferred to an external flash or hard drive
- maintain the data in encrypted files using VeraCrypt encryption software
- utilize the services of an ISP that is independent of the university so that we have control over the data
- ensure that only authorized members of the research team have access to the raw data
- transcribe all open-ended responses to survey questions and all responses to the (optional) interview component, anonymize to the extent possible, and destroy all audio files once transcribed

Once complete, the information provided will be analyzed using both qualitative (NVivo) and quantitative (SPSS) data analysis software, and the results disseminated in multiple fora, including: (a) articles for journals such as the Journal of Academic Ethics; (b) conference presentations and workshops for such organizations as CAREB; and (c) a Master’s thesis that will be prepared by team member Ms. Ivers. A summary also will be made available to all research participants who request it.

If you have any further questions or comments about this research, please feel free to contact Dr. Ted Paly, the principal investigator, at @sfu.ca or . Your consideration of this request is most appreciated.
Appendix B.

National Survey Regarding Institutional Confidentiality Policies

Welcome to this national survey of REBs regarding institutional policies for the protection of research confidentiality that is being conducted by Dr. Ted Palys (principal investigator) and Ms. Aaren Ivers (student collaborator) with funding supplied by an SSHRC small grant. To begin, we would appreciate if you would provide some basic "demographic" information about you and your institution that will allow us to describe the sample of institutions who are represented in our study.

Q01. In what type of institution does your REB operate?

- a university or college that offers degrees up to and including the PhD and has a medical school associated with it
- a university or college that offers degrees up to and including the PhD and does NOT have a medical school associated with it
- a university or college that does NOT offer diplomas or degrees beyond the Bachelor’s level
- another type of post-secondary educational institution other than those described above
- a hospital and/or medical school affiliated with a university
- another type of research institution

Q03. What is your primary role within the institution in relation to ethics?

- Chair of the institution's REB (or one of them if more than one)
- Member of the institution's REB
- Staff member of the institution's ethics office
- Legal adviser to the REB
- Senior administrator at the institution
- Other

Q04. With which of the following granting agencies has your institution filed an MOU to allow you to apply for grant funds? [Check all that apply]

- CIHR (Canadian Institutes for Health Research)
- NSERC (National Science and Engineering Research Council)
- SSHRC (Social Science and Humanities Research Council)
- I’m not aware of which granting agencies we have filed an MOU with

Q05. Within the past year, which of the following types of research projects have come before your REB for review? [Check all that apply]
identifiable information regarding the existence of or risk factors associated with HIV, AIDS, and other
STDs
identifiable information regarding sexual attitudes, preferences, or practices
identifiable information that reveals the use of alcohol, drugs, or other addictive products
identifiable information regarding illegal conduct
identifiable information that, if released, could be damaging to a participant's financial standing, employability, or reputation within the community
identifiable information that might lead to social stigmatization or discrimination if it were disclosed;
identifiable information in relation to participants' psychological well being or mental health
 genetic information, including studies that involve collecting and storing biological samples for future use
identifiable information in the context of epidemiologic studies
identifiable data in the context of a clinical trial
I'm not aware which of the above might have been considered over the last year

Q06. If a researcher were to submit a proposal that involves acquiring sensitive information that could cause harm to participants if disclosed, which of the following would your REB permit the researcher to do? [Check all that would be permissible]

☐ pledge that the information shared will remain "completely confidential" with the implicit or explicit implication that the researcher would go to jail rather than disclose the information, even if ordered by a court
☐ pledge that the information will remain confidential unless ordered by a court to disclose the information
☐ pledge that the information will remain confidential unless the researcher is subpoenaed
☐ pledge that the information will remain confidential unless the researcher is asked by a legal authority (e.g., police officer) to reveal it
☐ I don't know which of these would be allowed by the REB

Following a recent confidentiality case that arose at the University of Ottawa, the Interagency Advisory Panel on Research Ethics (PRE) published an interpretation regarding Article 5.1 of the TCPS, which states in part that, "Institutions shall support their researchers in maintaining promises of confidentiality." [Click here if you would like to see the full interpretation.] The interpretation explains in part that,

Institutions under whose auspices or within whose jurisdiction such research is being conducted should establish a policy that explains how it will fulfill its responsibilities to support its researchers. The policy should include an explanation of the nature and the scope of the support, a mechanism to determine the level of support in individual cases, the source of funding (e.g., dedicated fund, insurance, agreement with professional association) and any other relevant criteria. The institution should establish such a policy in collaboration with its researchers.

From Panel on Research Ethics website

Q07. Has your institution developed such a policy?
Q08. Rather than developing policies at every university in anticipation of generating a legal defense to threats to research confidentiality, some authors have suggested that Canada should develop statute-based legal protections for gathering research information where confidentiality is essential to gathering valid information and protecting research participants for harm for disclosure. Would you support such an initiative?

- Yes
- Maybe. Would need to see more of how they might work
- No

Thank you for completing the survey. We assume that respondents to our survey prefer that their responses remain confidential. However, if you have responded to any of the open-ended questions and/or supplied copies of or links to policies, you may not care if your institution is identified, or may prefer it. If so, please indicate your preference and the name of your institution in the space below. Please also use that space to make any other comments you wish about the survey and/or the issues it involves.

If you would like to receive copies of the results of this research, please either indicate so below (along with your email address) or send a separate email to Dr. Ted Palys at Simon Fraser University at palys@sfu.ca

☐ Yes I would like to receive a copy of the results of the study.

Please send it to me at:

We are hoping to interview a subset of REB Chairs in greater detail about the issues addressed in this survey. If you would be willing to partake in such an interview, please either indicate so below (along with your email address) or send a separate email to Dr. Ted Palys at Simon Fraser University at palys@sfu.ca

☐ Yes I would be willing to participate in an interview on the issue of confidentiality policies and confidentiality protections.

Please contact me to arrange a mutually convenient time.
Thank you very much for taking the time to complete this survey. By pressing "Submit" below, you indicate your consent for the inclusion of your data in our database.

SUBMIT
Appendix C.

STATEMENT CONCERNING INSTITUTIONAL SUPPORT TO RESEARCHERS IN MAINTAINING PROMISES
OF CONFIDENTIALITY

1. Statement

McGill University will support its researchers in maintaining promises of confidentiality made to
participants in a study carried out in accordance with an approval granted by a Research Ethics Board (REB)
recognized as acting on behalf of the University.

2. Nature of the support provided to researchers

This statement describes the support offered by the University to researchers where the confidentiality
of a participant’s information is threatened by third party action aiming to compel the disclosure of such
information.

3. Scope of the support provided to researchers

3.1 Support will be provided through the Advisory Council on Human Research Ethics (ACHRE) and
the Department of Legal Services. Depending on the specific circumstances of a case, support may take
several forms, such as:

- Advice on the extent of promises of confidentiality made to participants in accordance with the
  approval granted by the REB;
- Investigation of and advice on current best practices bearing on the matter;
- Advice on whether to seek the support of professional organisations to which the researcher
  belongs whenever ethical obligations may also derive from one’s professional obligations;
- Support in attempting to resolve the dispute with the third party seeking disclosure of participant
  information;
- Legal action or legal support to oppose third party action to compel disclosure of confidential
  participant information (subpoenas, search warrants, requests for access to documents, etc.).

3.2 In cases where there is an irreconcilable conflict between the researcher’s ethical obligations to
safeguard confidentiality of participant information (as approved by the REB) and the researcher’s legal
obligations, the University will provide the researcher the services of independent outside legal counsel.

3.3 The mandate given to outside counsel will be to advise the researcher on the personal
consequences of a possible decision to respect ethical obligations rather than legal obligations in
accordance with the mechanism described below. The purpose of the mandate will not be to provide
advice on the potential consequences of the researcher’s decision on the University itself or on other
parties.

4. Mechanism to seek and receive support

4.1 A researcher presented with a request for access to confidential participant information or an
action seeking to compel disclosure of such information shall seek the help of ACHRE as soon as possible.
4.2 ACHRE shall review the matter and seek any relevant information from the researcher and the REB as appropriate, including details of what may be disclosed if the request or order is enforced, and what promises of confidentiality were made to participants according to the REB approval.

4.3 ACHRE shall seek the advice of Legal Services whenever the request for disclosure is in the form of a legal proceeding seeking to compel the disclosure of participant confidential information.

4.4 Legal Services, with the cooperation of the researcher and ACHRE, may, in the name of the University (and of the researcher if deemed appropriate by Legal Services) take reasonable lawful measures to prevent the disclosure of confidential participant information.

4.5 In the event of an irreconcilable conflict between the researcher’s ethical obligations to safeguard confidentiality of participant information (as approved by the REB) and the researcher’s legal obligations, Legal Services shall retain the services of independent outside legal counsel for the purpose of advising the researcher as described in paragraphs 3.2 and 3.3. Except at the request of, or with the express consent of the researcher, such advice shall be confidential and privileged, and shall not be shared with the University.

5. Funding of the support

5.1 The services of ACHRE and Legal Services as described in this policy are provided to the researcher free of charge.

5.2 The services of outside counsel retained by Legal Services in accordance with paragraphs 4.5 are covered by the University.

April 2015

Advisory Council on Human Research Ethics
Office of the Vice-Principal (Research and International Relations)
Department of Legal Services