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Chapter 9

Eight Challenges to Research Confidentiality in Canada: Invoking and Protecting Research-Participant Privilege

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Contents

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[**] John Lowman is Professor Emeritus in the School of Criminology at Simon Fraser University (SFU). Since 1977 he has studied prostitution law, prostitution law enforcement, and the practice of sex work in Canada. While planning to conduct research with Professor Ted Palys on escort services and body rub parlours in 1997, the Simon Fraser University research ethics administration attempted to force SFU researchers to limit confidentiality to the "extent permitted by law". The University argued that, because a subpoena effectively represents the limit of the law, if a researcher receives a subpoena for confidential information, they must disclose it. Lowman and Palys's refusal to comply with this "law-first" doctrine of research ethics edict led to their 22-year collaboration articulating an alternative ethics-first perspective on the ethics and law of research confidentiality, culminating in their book *Protecting Research Confidentiality: What happens when ethics and law collide* (Ontario: Lorimer, 2014). We thank Greta Bauer and Russel Ogden for their comments on an earlier version of this chapter.

> [L]egal and ethical approaches to issues may lead to different conclusions. The law tends to compel obedience to behavioural norms. Ethics aim to promote high standards of behaviour through an awareness of values, which may develop with practice and which may have to accommodate choice and liability to err. [A]lthough ethical approaches cannot preempt the application of the law, they may well affect its future development ...[1]

I. Introduction

In the United States since 1970, there have been dozens of attempts by third parties to use legal processes to obtain confidential research information, including the identities of research participants. So highly valued is research confidentiality to the research enterprise that these attempts have rarely succeeded.[2] Indeed, the Federal government and numerous state legislatures have enacted shield laws to protect research confidentiality. As of the time of writing in 2018, Canada has seen eight cases of lawful challenges to research confidentiality, the first of which did not occur until the mid-1990s. The ensuing chapter considers what we can learn from these challenges about the defence of research confidentiality in Canada. The first section of the chapter describes the eight challenges. The second section takes stock of what that experience has revealed about the ethical integrity of links in the chain of research confidentiality protection, including researchers, research institutions, the Federal bodies responsible for the oversight of research ethics in Canada, and the courts and other legal bodies responsible for adjudicating such challenges. The conclusion reflects on how researchers might best protect research confidentiality in the current Canadian legal milieu.

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1 *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (Ottawa: Public Works and Government Services Canada, 2005), online: < www.pre.ethics.gc.ca/eng/archives/tcps-eptc/Default > .

2 We are aware of four such cases, which we describe in Ted Palys & John Lowman, "Anticipating Law: Research Methods, Ethics and the Law of Privilege" (2002), 32:1 Sociological Methodology 1. We contend that, in each of these cases, the courts would have protected research confidentiality if the research had been designed with legal challenges in mind.

II. Eight Challenges to Research Confidentiality in Canada

Of the eight formal legal challenges to research confidentiality in Canada, four have involved the assisted suicide research of Russel Ogden. The first time any third party made a lawful challenge to research confidentiality in Canada was in 1994 when the Vancouver Coroner subpoenaed former MA student Ogden, of Simon Fraser University's (SFU's) School of Criminology, requiring him to appear at an inquest into the death of an unknown female.

A. Challenge 1: Assisted Suicide, the First Coroner's Challenge to Ogden's Research

For his 1994 Masters research, Ogden interviewed persons who had participated in the assisted suicides of HIV/AIDS sufferers at a time when an HIV/AIDS diagnosis was a death sentence and we knew little about the practice of assisted suicide and euthanasia. The Coroner wanted to know the identities of two individuals who were involved in an apparent assisted death described in a newspaper article.[3] The Coroner's inquest led him to Ogden's MA thesis, which described interviews with a physician who had refused to assist in the suicide and another person who had been present at the death. The subpoena marked the first time a legal authority ordered a Canadian researcher to disclose confidential information and threatened him with a contempt of court charge if he did not comply. Ogden was willing to assist the Coroner by discussing his findings, but in keeping with the ethical standards of his discipline and SFU's ethics policy, refused to name any of his participants.

While Ogden rose to the occasion, we cannot say the same for SFU's administration. Lamentably, SFU passed on the opportunity to offer a forceful defence of academic freedom, the value of research to the courts and society more generally, and the importance of research confidentiality to that contribution. Instead, it abandoned Ogden and his research participants.[4] Ogden would go on to offer that defence nonetheless by invoking the Wigmore criteria, which the Supreme Court of Canada has ruled is the appropriate test for claims to privilege made on a case-by-case basis.[5] The

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[3] Lyn Cockburn, "An Act of Courage", *The Vancouver Province* (May 12, 1991) 29.

[4] After an initial complete refusal, Ogden's senior supervisor made a final plea to the SFU president, who offered $2,000 "on compassionate grounds". Ogden's legal fees amounted to $11,367.38; see John Lowman & Ted Palys "Ethics and Institutional Conflict of Interest: The Research Confidentiality Controversy at Simon Fraser University" (2000), 2:4 Sociological Practice: A Journal of Clinical and Applied Sociology 245.

[5] Wigmore, a former Dean of Law at Northwestern University, first articulated the test in John Henry Wigmore, *A treatise on the system of evidence in trials at common law, including the statutes and judicial decisions of all jurisdictions of the United States, England, and Canada* (Boston: Little, Brown, and Company, 1905).

Coroner accepted Ogden's arguments, recognizing that the information he sought would not exist were it not for Ogden's pledge of confidentiality, which he was ethically bound to maintain. Underlining the importance of research evidence to policy and law-making processes, Ogden also testified before Parliamentary and Senate subcommittees investigating assisted suicide and gave dozens of interviews to media looking for an expert to comment on assisted suicides that were making headlines at that time.[6]

SFU's treatment of Ogden was the beginning of a 20-year discussion at SFU, and nationally, regarding potential conflicts between ethics and law when protecting research confidentiality.[7] After an internal investigation concluded that SFU should have fully supported Ogden and his research participants in court, the president apologized and reimbursed his legal fees in addition to several months of wages Ogden lost because of the stress of the proceedings.

B. Challenges 2 and 3: Ogden Subpoenas 2 and 3

In 1999, Kwantlen University College[8] employed Ogden as a sessional instructor. In 2004, he became a full-time Kwantlen faculty member. While at Kwantlen, Ogden continued his research on assisted suicide and euthanasia. Twice while he was conducting this research — first in 2003 and again in 2004 — a Crown prosecutor subpoenaed Ogden in relation to the prosecution of Ms. Evelyn Martens for aiding or abetting two suicides. Ogden was observing her court appearances as part of his research.

The Crown issued the first subpoena to Ogden to attend Martens' preliminary hearing. Because he was only a contract faculty member at Kwantlen, Ogden contested the subpoena without institutional support. He informed the prosecutor that the subpoena was an abuse of process. Rather than being based on evidence that he was a material witness, it was a fishing expedition to determine what information Ogden might have about the accused.

Although the Crown prosecutor ultimately withdrew the subpoena, it damaged Ogden's research nevertheless. Because he was a prospective material witness, the rules of evidence meant that Ogden was unable to attend several days of Martens' preliminary hearing. After the subpoena was withdrawn, the Crown prosecutor apologized to Ogden for the inconvenience to his research and assured him that he would not be called as a witness when the case went to trial.

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6 Most notorious were Ms. Sue Rodriguez, who petitioned the Supreme Court of Canada for the right to an assisted death after she became too sick to take her own life, and Dr. Jack Kevorkian ("Dr. Death") in the United States.

7 Ted Palys & John Lowman, *Protecting Research Confidentiality: What happens when law and ethics collide* (Toronto: Lorimer, 2014) [Palys & Lowman, *Protecting*].

8 In 2008 Kwantlen University College became Kwantlen Polytechnic University.

A different Crown prosecutor was assigned to Martens' trial. The trial prosecutor again subpoenaed Ogden, who responded with a letter to the prosecutor saying that he would "take all necessary steps to resist any threat to academic freedom and the fundamental value of privacy for research participants".[9] Now that Ogden was a full-time Kwantlen faculty member (he became one that year) he approached the administration for assistance. When a Kwantlen-hired lawyer phoned the prosecutor asking for the Crown's justification for the subpoena, making clear that Kwantlen would contest it, the Crown again withdrew it.

C. Challenge 4: Bruckert, Parent, and Magnotta the Murderer

In 2012, Montreal police asked two University of Ottawa criminologists, Drs. Chris Bruckert and Colette Parent, to provide them with a copy of an interview they had done five years earlier in a study of sex workers and their clients. Determined to maintain the confidentiality of their sources, they put the interview transcript and audiotape in the hands of an attorney funded by the Canadian Association of University Teachers (CAUT). Police then served a search warrant on the attorney at his office, and seized the material, which they placed in a sealed envelope pending the court's review of a claim of privilege. It is difficult to see how an interview conducted five years before the accused and his victim first met would have evidentiary value, particularly given the wealth of other evidence linking the accused directly to the murder. For example, he had posted a video online of the killing and dismemberment of the body, among other gruesome acts, and security camera footage in the building where the murder occurred showed him carrying plastic bags that police later found to contain body parts. However, the police and Crown persisted.

Two aspects of the case are particularly noteworthy. First, while the two researchers were prepared to contest the search warrant, the University of Ottawa (U of O) was not. According to President Alan Rock:

> The University of Ottawa recognizes its role ... in safeguarding entrusted information. However, the University does not consider that its role extends to the payment of legal costs if researchers decide to challenge the seizure of research records in the context of criminal proceedings.[10]

In this troubling statement, Rock repeated what SFU had done to Ogden, but that SFU later recognized was a mistake. Rock's only offer was for a few hundred dollars to pay for the researchers' initial legal consultation.

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[9] Letter from Russel Ogden to Laura Ford (August 9, 2004).

[10] Canadian Association of University Teachers, "uOttawa criminologists go to court to protect research confidentiality" (2013), 60:1 CAUT/ACPPU Bulletin, online: < bulletinarchives.caut.ca/bulletin/articles/2013/01/uottawa-criminologists-go-to-court-to-protect-research-confidentiality > .

Fortunately, CAUT intervened and hired a lawyer, hoping that the U of O would acknowledge its responsibility for legal bills that eventually totalled $300,000.

The second and most notable aspect of the case is that Bruckert and Parent defended their participants in Quebec Superior Court by claiming a research participant privilege via the Wigmore criteria and won.[11] It was the first time that a Canadian court officially recognized a research-participant privilege.[12]

D. Challenge 5: Ogden Subpoenaed to Testify at the Inquest into a Self-Chosen Death

After Ogden became a full-time faculty member in 2004, he submitted all of his self-chosen death research proposals to the Kwantlen Research Ethics Board (REB) for approval. In developing his proposals, one important concern was ensuring that no individual who contacted him felt obliged to follow through with a suicide because he or she had agreed to allow him to observe it. Another was to ensure that his actions were independent of the deathing process so that he did not counsel, aid, or abet the suicide, all offences under Canadian criminal law.

On July 12, 2005, the Kwantlen REB approved Ogden's proposal to attend "NuTech"[13] and other self-chosen deaths. Ogden's original proposal was to attend a single death. Subsequently, the REB approved his attending multiple deaths. The Board issued Ogden an ethics certificate that had no expiry date.

Despite Ogden's ethical and legal precautions, Kwantlen balked. Seventeen months after receiving the initial REB approval, the Kwantlen Provost/VP-Academic told Ogden, "[y]ou are not to engage in any illegal activity including attending at an assisted death".[14] Kwantlen then commissioned a legal opinion after the fact. Although the attorney

[11] Ted Palys & David MacAlister, "Protecting Research Confidentiality via the Wigmore Criteria: Some Implications of *Parent and Bruckert v The Queen and Luka Rocco Magnotta*" (2016), 31:3 CJLS 473.

[12] Although the Vancouver Coroner had recognized the privilege in Ogden's case, a Coroner's inquest is not technically a "court of law." While the Coroner ruled in favour of Ogden's claim for a researcher-participant privilege, he ruled against three journalists who had written about the death, finding there was no journalist-source privilege in this case. However, the journalists appealed the Coroner's finding of contempt, arguing in BC Supreme Court in *Pacific Press Ltd v. Cain*, [1997] B.C.J. No. 1061 (B.C. S.C.), that the Coroner did not have the jurisdiction to find them in contempt. The court agreed, concluding that a Coroner's inquiry was not a "court of law" and that the Coroner should have asked the Supreme Court of British Columbia for a declaration of contempt.

[13] A NuTech death involves oxygen deprivation with helium; see Russel D. Ogden "Observing a Self-Chosen Death" in Jennifer M. Kilty, Maritza Felices-Luna & Sheri Fabian, eds, *Demarginalizing Voices: Commitment, Emotion, and Action in Qualitative Research* (Vancouver: UBC Press, 2014) 15.

[14] *Ibid.*

providing the opinion never read Ogden's legally and ethically nuanced research proposal, he asserted that Ogden attending a suicide would constitute a criminal offence. In contrast, when the Vancouver Police Department investigated two 2008 suicides that Ogden attended, the detectives concluded that he would likely know the boundaries of the law for counselling or aiding suicide and that there was no evidence of him committing an offence.[15]

Kwantlen's decision to stop REB-approved research attracted the attention of the Canadian Association of University Teachers. In 2008, CAUT commissioned an independent legal opinion that considered Ogden's actual research protocol, which he designed with the relevant case law in mind. When that opinion concluded Ogden's research protocol would allow him to attend a suicide without violating the criminal law, CAUT launched an investigation to ascertain whether Kwantlen's stop-research edict had infringed Ogden's academic freedom to conduct research. However, on November 19, 2008, Kwantlen president David Atkinson sent a memo to members of the sociology and criminology departments announcing that Kwantlen and the Kwantlen Faculty Association had reached a "settlement agreement" allowing Ogden to continue his research while on a two-year leave of absence, commencing on January 1, 2009. On hearing this news, CAUT ended its investigation.

While on leave, Ogden proceeded with his research on self-chosen death. However, he did not return to his regular teaching and administrative duties on January 1, 2011 as per the agreement. Ogden continued his research for another five years under a second confidential agreement. It was during this period when, in May 2014, the BC Coroner served Ogden with a summons to interview him concerning the 2012 death of one of his research participants. Ogden complied, attending the Coroner's office in Burnaby on November 13, 2014. Because the Coroner's examination could potentially compromise Ogden's confidentiality pledge to his research participants, he requested that Kwantlen provide legal support as per *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, 2010* (*TCPS2*) article 5.1, which requires that "... Institutions shall support their researchers in maintaining promises of confidentiality".[16]

Kwantlen refused, stating that the second confidential agreement (the one involving Ogden, the Kwantlen Faculty Association, and Kwantlen) meant that the institution did not have to provide Ogden with the legal support that *TCPS2* article 5.1 mandates. With Kwantlen reneging on its obligation under *TCPS2* to provide him with legal support, Ogden retained counsel to prepare for and represent him at the Coroner's hearing. During

[15] Ogden, *supra* note 13 at 33-34.

[16] *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, 2010* (Ottawa: Public Works and Government Services Canada, 2010) ch. 5, art. 5.1, online: < www.pre.ethics.gc.ca/pdf/eng/tcps2-2010/TCPS_2_FINAL_Web.pdf > [*TCPS2*].

the hearing, Ogden's attorney objected to several questions the Coroner posed on the ground that they would require a violation of Ogden's promise of confidentiality to his research participants. Each time, perhaps mindful of the 1994 Coroner's recognition of research-participant privilege when a Coroner first subpoenaed Ogden, the 2014 Coroner withdrew the question. The bill for Ogden's lawyer came to $22,806.01.

Kwantlen's intransigence led one of us to submit a complaint to the Secretariat for Responsible Conduct in Research (Secretariat) that Kwantlen violated *TCPS2* article 5.1. However, at the time of writing nearly four years later, the Secretariat has yet to complete its processing of this complaint (unlike the strict timelines it imposes on institutions for handling research ethics complaints, the Secretariat imposes none on itself). It appears the delay has related mostly to Kwantlen's refusal to divulge the contents of its second confidential agreement with Ogden.

The presumption embedded in article 5.1 is that universities must provide legal support for researchers who undergo ethics review and follow their REB-approved research protocols. Given that Ogden, in his capacity as a Kwantlen faculty member, followed his Kwantlen-approved REB research protocol, it is difficult to understand why the Panel on Research Ethics (PRE)/Secretariat would allow a university to justify abrogating its responsibilities under *TCPS2* by hiding behind this shield of confidentiality. Given the allegation that Kwantlen is using the agreement to conceal its violation of *TCPS2* article 5.1, Kwantlen should give the PRE/Secretariat permission to see the relevant clauses to ascertain whether the institution has improperly circumvented article 5.1. If Kwantlen refuses, it should be held to its default obligation to provide legal support and be required to reimburse Ogden's legal expenses.

E. Challenge 6: Tilting at Windmills, the Maillé Case

In 2010, Marie-Ève Maillé was conducting research for her doctorate in communications at the Université de Québec à Montréal (UQAM). Her study involved surveys and interviews with people living in an area where Éoliennes de l'érable (Maple Wind Turbines) had established a wind farm. She gathered all the information under a promise of confidentiality. Several years later, the citizens in her research area began a class action lawsuit against Éoliennes de l'érable. They asked Maillé if she would provide expert testimony as to her research findings. She agreed. The wind turbine company then sought a subpoena requiring her to produce the names of all her participants and hand over her raw data — transcripts, tapes, field notes — ostensibly to be able to evaluate her methods and conclusions.[17]

[17] Diane Peters, "Quebec researcher in legal fight over research confidentiality", *University*

UQAM's initial response upon hearing about the subpoena was to distance itself from her research by defining the challenge as Maillé's problem: "[y]ou are the owner of the intellectual property rights of your thesis including your research data. This research data does not belong to the university".[18] By this means, UQAM denied its responsibility to defend Maillé's research participants, and advised Maillé to withdraw as an expert witness.[19] It was not until colleague Chantal Pouliot published a letter signed by her and 200 other academics in the newspapers *Le Soleil*[20] and *Le Devoir*[21] protesting UQAM's action that UQAM offered to provide legal representation.

UQAM's prevarication came close to undermining the case and the significant precedent set by Bruckert/Parent in the Magnotta trial. When she was unrepresented, Maillé told the Court that she could not share her data because of her promise of confidentiality and submitted a copy of her consent statement guaranteeing confidentiality. It got her nowhere. In 2016, the Court denied her application and ordered her to produce her data.[22] She refused and sought instead to withdraw her offer to provide expert testimony. However, the wind turbine company continued to insist that she disclose her data. After securing pro bono representation, the Court granted Maillé a new hearing. This time her attorney applied the Wigmore criteria, contending that the information should remain confidential. The Court agreed and quashed the order.[23] Maillé never did provide expert testimony.

F. Challenge 7: Transgender Identity, the Bauer Case

Dr. Greta Bauer is a Professor of Epidemiology and Biostatistics in the Schulich School of Medicine and Dentistry at Western University in London, Ontario. For years, she has led the survey portion of the Trans

Affairs (January 18, 2017), online: < www.universityaffairs.ca/news/news-article/quebec-researcher-legal-fight-research-confidentiality/ > [Peters, "Quebec researcher"].

18 Ulysse Bergeron, "Une chercheuse force par la justice de révélr l'identité de ses sources", *Radio-Canada* (October 31, 2016), online: < ici.radio-canada.ca/nouvelle/811463/source-identite-uqam-chercheuse-eolienne-entreprise-ordonnance-scientifiques-canadiens > . The original French is: Vous êtes la titulaire des droits de propriété intellectuelle de votre thèse incluant notamment vos données de recherche. Ces données de recherche n'appartiennent pas à l'université.

19 Peters, "Quebec researcher", *supra* note 17.

20 Chantal Pouliot, "L'affaire Maillé, ou l'avenir de la confidentialité dans la recherché scientifique", *Le Soleil* (November 3, 2016), online: < www.lesoleil.com/opinions/point-de-vue/laffaire-maille-ou-lavenir-de-la-confidentialite-dans-la-recherche-scientifique-71b9d1aae73f2224d8a1d7be17fb4dae > [Pouliot, "L'affaire Maillé"].

21 Chantal Pouliot, "L'affaire Maillé, ou l'avenir de la confidentialité dans la recherché scientifique", *Le Devoir* (November 3, 2016), online: < www.ledevoir.com/opinion/libre-opinion/483756/l-affaire-maille-ou-l-avenir-de-la-confidentialite-dans-la-recherche-scientifique > .

22 *Rivard c. Éoliennes de l'Érable, s.e.c.*, 2016 QCCS 98 (C.S. Que.).

23 *Rivard c. Éoliennes de l'Érable s.e.c.*, 2017 QCCS 2259 (C.S. Que.).

PULSE Project, "which works with community partners to collect physical and mental health data on the trans population in Canada".[24] Her team's quantitative surveys represent the first and most comprehensive study of transgender health ever conducted in Canada, involved more than 1500 variables, and sought wide-ranging and very personal information. In 2015, the Centre for Gender Advocacy in Montreal initiated a *Charter* challenge focussed on Quebec's rules with respect to when transgender persons can legally change their gender on official documents. Knowing that Bauer found suicide rates are lower among those whose official documents reflect their lived gender, the Centre approached her to serve as an expert witness, which she agreed to do pro bono.

In 2016, the Attorney General (AG) of Quebec sought to have Bauer disclose all her raw data so that the AG's experts could evaluate it. Acknowledging the sensitivity of the information, the AG offered to have the Court place conditions under which the AG's experts could examine the data. Bauer refused, explaining in an email to a legal advisor at Western that she and her team had spent three years building trust with trans communities, had emphasized data security in meetings with prospective respondents, and believed that even with the data anonymized, they had information on so many variables that some respondents might be identifiable. If word got out that the researchers had shared raw data with anyone not described in consent documents, let alone a government department arguing against trans rights, the trust that made the research possible likely would be destroyed.

Unlike the many other university administrators who showed researchers the door when they requested legal support, Western's administration was immediately ready to protect Bauer's research participants. According to Peters:

> From there, Mark Daley, the associate vice-president of research, Western's legal team and Ms. Boctor, a partner with Irving Mitchell Kalichman LLP who is representing the Montreal centre at the heart of this case, took over. They submitted affidavits to the court, including a letter written by Dr. Daley explaining that opening up research data to the courts would put a chill on academic projects, particularly those involving vulnerable populations. "We have to protect our research subjects," said Dr. Daley. "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".[25]

The Court decided that Bauer's offer to share printouts of statistical results, survey instruments, code books and be cross-examined provided more than

[24] Diane Peters, "Another case involving research data confidentiality hits the courts", *University Affairs* (April 24, 2017), online: < www.universityaffairs.ca/news/news-article/another-case-involving-research-data-confidentiality-hits-courts/ > [Peters, "Another case"].

[25] *Ibid.*

an adequate opportunity for the Attorney General to challenge her findings. In contrast to the Maillé case, the Court noted that Bauer's studies were part of her ongoing research activity: "[t]he Trans PULSE study was not produced for the purposes of the present litigation".[26] The Court continued:

> [I]t would be odd and undesirable if the researchers who have undertaken obligations of confidentiality with respect to research participants be systematically forced to breach their ethical obligations if they want to be authorized to act as experts before the Courts regarding their work. If this were to be the case, Courts would ultimately be forced to systematically rely on experts who have a less intimate, less direct and sometimes less profound knowledge of the subject matters at issue.[27]

With those words, the Court dismissed the Attorney General's application.

G. Challenge 8: Antidepressants and Neurodevelopmental Disorder, the Boukhris Case

Dr. Anick Bérard is a Professor in the Faculty of Pharmacy at the Université de Montréal and the Sainte-Justine University Hospital Research Centre. To facilitate her research, the Quebec Health Ministry had granted her access to a database pertaining to 439,003 pregnancies and 245,502 children between 1998 and 2015. The Quebec Ministry of Health, Ministry of Education, Quebec Health Insurance Board and the Quebec Institute of Statistics compiled the database.[28] The confidentiality agreement pertaining to the data gave access only to Bérard and members of her research team who signed an agreement that they, too, would maintain confidentiality of the data.[29] When Bérard became the senior supervisor of pharmaceutical sciences doctoral student Takoua Boukhris, she gave Boukhris permission to access the database for her dissertation research. Among the team's findings was a causal link between a GlaxoSmithKline (GSK) antidepressant and autism spectrum disorder.

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[26] *Centre de lutte contre l'oppression des genres | Centre for Gender Advocacy c. Québec (Procureure générale)*, 2016 QCCS 5161 (C.S. Que.) at para. 49 [*Centre de lutte contre l'oppression des genres*]. The quote is from an unofficial translation. The original French is: "L'étude Trans PULSE n'a pas été générée aux fins du présent litige".

[27] *Ibid.* at 71.

[28] Mirna Djukic, "Recherche universitaire: une autre Québécoise sommée de fournir ses données", *LaPress* (October 16, 2017), online: < www.lapresse.ca/actualites/justice-et-faits-divers/actualites-judiciaires/201710/15/01-5140087-recherche-universitaire-une-autre-quebecoise-sommee-de-fournir-ses-donnees.php > .

[29] *GlaxoSmithKline v. Boukhris, Conley, Gass-Gilchrist, Bérard, CHU Ste-Justine and Boukhris* (September 14, 2017), Doc. 500-17-100299-174 (Montréal, Qué Cour Supérieure (Chambre civile)) (pourvoi en sursis d'exécution et en rétraction de jugement à la demande d'un tiers amendé (appeal on a stay of execution and withdrawal of judgment at the request of a third party as amended)) [*GSK*, "Pourvoi en sursis"].

In June 2017, two mothers in Delaware filed a lawsuit against GSK alleging that one of the company's antidepressants that doctors prescribed during their pregnancies had caused their children's autism spectrum disorder. The mothers cited Boukhris and Bérard's research in support of this claim. Consequently, GSK sought access to their raw data in order to challenge the causal link they claimed to have found.[30]

Because the researchers live in Canada, GSK initiated proceedings in Quebec Superior Court to gain access to their raw data. It was of no small significance that GSK approached the wrong person — Boukhris rather than her supervisor — requesting her cooperation. Court documents reveal a perfect storm of adverse circumstances besetting the researchers. Boukhris was on maternity leave and Bérard on vacation when the initial mailed letters arrived. Boukhris's child was hospitalized at a crucial juncture in the legal process. Apparently, there was no communication for months between the two researchers about the legal challenge, even after both returned. Boukhris was powerless in any event because Bérard controlled the data, which in turn was subject to the agreement Bérard had signed. Despite the GSK attorney's efforts to determine whether the researcher planned to contest any order, and warnings to Boukhris that court decisions would be made in her absence, neither Boukhris nor Bérard appeared in court on September 5, 2017 when GSK sought its order for disclosure.[31] It also appears that, despite the advanced stage of the proceedings at that time, administrators at neither the Université de Montréal nor CHU Ste-Justine knew anything about the legal challenge.[32]

At the hearing, the judge asserted erroneously that the data were "public" and thus not subject to a confidentiality agreement. With no researchers in court to correct his error, the judge ordered that the researchers disclose the data with names redacted. The resulting order required the researchers to produce the name-redacted raw data, all proposals and study protocols, variable codes and printouts, any unpublished studies, and all protocols/data/printouts associated with those. They were to produce the information at the offices of GSK lawyers on September 15, 2017 and submit to questioning about them on October 6.

Realizing the significance of the threat to research confidentiality the disclosure order posed once she knew about it, Bérard informed CHU Sainte-Justine and the Université de Montréal about the order. Both institutions responded immediately and submitted an application a day later requesting the Superior Court of Quebec quash the disclosure order.[33]

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30 *GlaxoSmithKline v. Boukhris, Conley and Gass-Gilchrist* (October 4, 2017), Doc. 500-17-100299-173 (Montréal, Qué Cour Supérieure (Chambre civile)) (motion by Applicant for Communication of Certain Documents Further to the Judgment of the Honourable Justice Riordan).

31 *Ibid.*

32 *GSK*, "Pourvoi en sursis", *supra* note 29.

However, on February 14, 2018, before litigation on the revocation application began, GSK announced that issues relating to the research had been settled out of court, and that the company would abandon all previous judgments made in its favour.[34]

III. Lessons from the Eight Challenges

In what follows, we take stock of what these conflicts between law and research confidentiality have shown in terms of the kinds of research involved in legal challenges, the way that various actors have responded to these challenges, and the implications of their experience for how to move forward.

A. The Challenges

Despite the limited number of cases in Canada, experience shows that lawful challenges to research confidentiality can come from almost anywhere. The most common discipline is criminology, with Ogden's four subpoenas and the Bruckert-Parent case all involving criminal behaviour. But challenges to research confidentiality are not limited to criminology. The Maillé case arose from a dissertation in Communications, while the Bauer and Boukhris cases involved health disciplines. The US experience reveals even greater disciplinary heterogeneity. Nevertheless, criminology and health studies are the two most common areas for subpoenas in the United States, which has a far more extensive experience with legal challenges to research confidentiality.[35] These are also the two research areas for which US federal and state legislatures have enacted statute-based protections. The Federal research shield laws include Privacy Certificates for some criminological research and Certificates of Confidentiality for a broad array of health research.[36]

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[33] *GlaxoSmithKline v. Boukhris, Conley, Gass-Gilchrist, Bérard, CHU Ste-Justine and Boukhris* (14 September 2017), Doc. 500-17-100299-174 (Montréal, Qué Cour Supérieure (Chambre civile)) (pourvoi en sursis d'exécution et en rétraction de jugement à la demande d'un tiers (appeal on a stay of execution and withdrawal of judgment at the request of a third party)).

[34] *GlaxoSmithKline v. Boukhris, Conley, Gass-Gilchrist, Procureur Général du Québec and Commission d'access È l'information du Québe* (February 12, 2018), Doc. 500-17-099729-173 (Montréal, Qué Cour Supérieure (Chambre civile)) (désistement total de jugements).

[35] For a sample of cases, see Palys & Lowman, *Protecting*, *supra* note 7. See also Joe S. Cecil & Gerald T. Wetherington, eds, "Court-Ordered Disclosure of Academic Research: A Clash of Values of Science and Law" (1996), 59:3 Law & Contemp Probs 1 (Cecil and Wetherington's classic volume discussing US cases reveals a similar heterogeneity of affected disciplines).

[36] Ted Palys, James Turk & John Lowman, "Statute-Based Protections for Research Participant Confidentiality: Implications of the US Experience for Canada" (2018), 33:3 CJLS 381.

Most Canadian cases involved a subpoena or application for a disclosure order, but the Bruckert-Parent case involved a search warrant. Cases arose in both criminal and civil litigation; the latter involved a *Charter* challenge in one case, class action litigation in the second, and individual litigation initiated in another country in the third. In two civil cases, the researchers were expert witnesses called by one side and challenged by the other while, in a third, the researchers' data were subpoenaed when the applicants in the suit cited the research in support of their claim. In the criminal cases, a third party — the police, the Crown, a Coroner — thought confidential research information would be useful to them in a prosecution or coroner's inquest.

Challenges to research confidentiality usually occur well after research is finished and are usually a surprise. Because the onus is on the researcher to justify a claim of privilege, preparation of a legal argument and attending hearings can become the central focus of a researcher's life for an extended period. Although it is easy to understand why some research could prove useful for third-party legal proceedings — for example, why a Coroner might seek information relevant to an inquest — other subpoenas, such as in the Maillé and Boukhris cases, came out of the blue. As one interviewee in a recent study of REB Chairs noted:

> ...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.[37]

The quote adds the spectre of lawful challenges to research confidentiality becoming more numerous, especially as researchers become more interested in the application of their work to applied problems and social issues, and lawyers take the opportunity to challenge their evidence. Because the onus for justifying why a court should quash a subpoena is currently on the researcher, one concern is that lawyers may use subpoenas to intimidate prospective expert witnesses into declining to testify.

B. Roles and Responses

Various actors become involved when a legal challenge arises, including the researcher, the REB, the university administration, the federal Secretariat on Responsible Conduct of Research and the courts. We consider in turn how each has responded in the eight challenges to date.

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[37] Ted Palys & Aaren Ivers, "'Hope for the Best, Plan for the Worst': Understanding Administrative Inertia in Developing Confidentiality Protection Policies" (2018), 13:4 Journal of Empirical Research on Human Research Ethics 438.

1. Researchers

Generally, researchers have been the strongest link in the chain protecting research participant confidentiality, although there have been exceptions. Most researchers have lived up to their promises to participants notwithstanding the personal risk they incur by doing so. Russel Ogden and Marie-Ève Maillé both took steps to protect their participants even after their institutions had all but abandoned them. While informing her university's legal advisor of the service of the subpoena, Greta Bauer stated that, although she did not relish the prospect of going to jail, she could not imagine violating the pledge of confidentiality she knew was essential for her research to take place.

The most egregious exception is the research assistant who interviewed Luka Magnotta when he was a participant in Bruckert and Parent's study of sex workers. The research assistant voluntarily approached Montréal police after Magnotta's name appeared in the news as the prime suspect in the murder to let them know about the interview he had done five years earlier with Magnotta, who was a sex worker at the time. The research assistant contacted police without consulting Bruckert or Parent, despite the extensive training they provided, which emphasized the importance of confidentiality to the project. In a talk she gave at SFU reflecting on her experience, Bruckert noted that confidentiality precautions are only as good as your weakest link, which in this case was the research assistant.[38]

At a different level, Boukhris and Bérard's experience is a reminder that the justice system grinds along even when researchers do not receive letters or ignore them. Their experience also shows why institutions should have policies outlining the steps researchers should take to receive appropriate legal support.

2. Research Ethics Boards

The biggest transition in REB dynamics came in 1998 when federal granting agencies released the first edition of the *Tri-Council Policy Statement on Responsible Conduct* (*TCPS*), to which institutional ethics policies had to conform. The *TCPS* wrought two institutional changes of particular significance: (1) the requirement that REBs be constituted independent of an institution's administration in order to avoid the appearance of institutional conflict of interest; and, for the same reason, (2) the requirement that institutional administrators do not appoint REB members.

[38] Christine Bruckert, "Wrong Case, Right Decision: Lessons Learned at the University of Ottawa" (Paper delivered at the School of Criminology, Simon Fraser University, November 4, 2015).

The impact of this transition was evident in the changes that occurred between the Ogden case at SFU involving the Coroner, and the one involving Bruckert and Parent at the U of O. At SFU in the pre-*TCPS* era, the VP-Research chaired the University Research Ethics Review Committee and appointed its members. When the Coroner subpoenaed Ogden, not one of the VP's appointees stepped forward to remind SFU of its responsibility to protect research participants.[39] In contrast, with the *TCPS* requiring REB independence from administration influence, U of O REB members publicly lamented the university's stance toward Bruckert and Parent, reminding the administration of its institutional obligations, and warning of the negative repercussion of its inaction.[40] Their advice proved prescient.

3. *University Administrators*

If research confidentiality protection is only as strong as the weakest link, then a strong candidate for that dubious distinction is university administrators. Out of the eight Canadian challenges to date, no group has been more out of step with ethical principles and practices than university presidents and vice-presidents of research. When Ogden sued SFU in Small Claims Court trying to recoup his legal expenses, the president and VP-research stated under oath that ethics had nothing to do with their decision to refuse funding for Ogden's legal defence. Their primary concerns were image and liability management.[41]

By the time Bruckert and Parent's attorney received the search warrant, *TCPS2*[42] had made clear that institutions were obliged to support their researchers in resisting legal challenges to research confidentiality. When U of O did not, it was fortunate for Bruckert and Parent, and the research community more generally, that CAUT and then-Executive Director Jim Turk understood the importance of the case. CAUT paid for the researchers' legal support on no more than the hope that the U of O would at some point live up to its obligations. A complaint was registered against U of O[43] for failure to comply with *TCPS2*, and the Interagency

[39] Palys & Lowman, *Protecting*, *supra* note 7.

[40] Canadian Association of University Teachers, "REB members deplore uOttawa's refusal to defend confidentiality" (2013), 60:4 CAUT/ACPPU Bulletin, online: <bulletin-archives.caut.ca/bulletin/articles/2013/04/reb-members-deplore-uottawa-s-refusal-to-defend-confidentiality>.

[41] *Ogden v. Simon Fraser University*, 1998 CarswellBC 3260, [1998] B.C.J. No. 2288 (B.C. Prov. Ct.); Nicholas Blomley & Steven Davis, "Russel Ogden Decision Review" (Report prepared for the president of Simon Fraser University, October 1998), online: <www.sfu.ca/~palys/ogden.htm>.

[42] *TCPS2*, *supra* note 16.

[43] Canadian Association of University Teachers, "Complaint Targets uOttawa for Failure to Defend Confidentiality" (2013), 60:6 CAUT/ACPPU Bulletin, online: <bulletin-archives.caut.ca/bulletin/articles/2013/06/complaint-targets-uottawa-for-failure-to-defend-confidentiality>.

Advisory Panel on Research Ethics agreed: the U of O had indeed violated *TCPS2*'s provisions regarding support. While still arguing that *TCPS2* needed to indicate more clearly what it meant by "support," the U of O agreed to reimburse $150,000 of the $300,000 that CAUT had paid. The U of O should have paid the entire legal fee, but the Secretariat agreed that, because the policy did not clearly define the meaning of support, it should not penalize the U of O for failing to live up to its obligations under *TCPS2*.[44]

The experience with Kwantlen was mixed. On the first occasion (Challenge 3), when the Crown subpoenaed Ogden while he was observing the Martens trial and Kwantlen made clear that it would contest it, the Crown withdrew the subpoena. However, when the Kwantlen REB approved Ogden's proposal to observe self-chosen deaths, Kwantlen sought to shut it down, asserting that his observing a suicide would amount to aiding and abetting it, an offence under Canadian criminal law. When a CAUT-sponsored legal opinion challenged that view, Ogden proceeded with the death-observation research for seven years, but under circumstances that are unknown because of two confidentiality agreements he made with Kwantlen. When a Coroner subpoenaed Ogden in 2014, Kwantlen refused to provide legal representation because of a clause in the second confidential agreement, but in apparent violation of *TCPS2*.

The Maillé case at UQAM is another example of a researcher following the institution's policies and passing REB review only to find herself abandoned when a third party challenged the confidentiality essential to her research.[45] After arguing that Maillé should bear all the responsibility, the university relented only when newspapers reported the dispute, and two hundred academics signed a letter castigating UQAM for abdicating its ethical responsibilities and ignoring its long-term effects on the academy's ability to do research on sensitive topics.[46]

It was not until the Bauer case that a university — Western — carried out fully its responsibilities under *TCPS2*. Similarly, in the Boukhris case, the Université de Montréal and Sainte-Justine Hospital made clear they would support their researchers and contest the order for disclosure.

When universities *do* support researchers and their participants, the results have all been positive. When a challenge has gone to a hearing, as in the Bauer case, it turned out positively. Bruckert and Parent fared similarly well, at least in terms of outcome, when they were able to secure independent

[44] The Secretariat acquiesced to U of O's argument that it was not clear what *TCPS2* meant by "support".

[45] The original response of SFU to the Ogden subpoena was to say that, because he had already defended his MA thesis and graduated, Ogden was no longer an SFU student and thus the university had no further obligation to him despite the fact he conducted the research under its auspices and according to its policies.

[46] Pouliot, "L'affaire Maillé", *supra* note 20.

legal representation. In contrast, all was almost lost when UQAM abandoned Maillé and she represented herself. Similarly, without legal guidance, Université de Montréal/CHU Ste-Justine researchers Boukhris and Bérard failed to appear at a crucial hearing in which an order for disclosure was obtained based on erroneous information that easily could have been corrected. These experiences are consistent with the literature in the United States, which suggests that quick assertive legally informed responses to subpoenas benefit researchers and universities alike.[47]

Some institutional reluctance to commit fully to defending research confidentiality continues. When the Secretariat affirmed that article 5.1 of *TCPS2* requires institutions to provide legal support for researchers facing challenges to research confidentiality,[48] it also suggested that institutions develop policies articulating how they will provide that support. Two years after that advice, in a national survey of REBs and ethics administrators, Palys and Ivers found that only one institution in Canada — McGill — had developed a policy that met all of PRE's criteria.[49] A significant factor explaining administrative prevarication is university administrators' desire to keep support discretionary. For example, in its submission to a PRE/Secretariat consultation, U of T's vice-president of Research and Innovation explained that:

> While we believe it is important to provide all appropriate supports to researchers in the face of attempts by legal process to compel disclosure, the manner and extent to which those supports are made should remain at the discretion of the institution providing them. We believe it is appropriate to have a provision encouraging, rather than mandating, the provision of legal advice in situations where the researcher acts in good faith and within their scholarly capacity. . . . We expect that the interests of the participants, researchers and the institution will in most cases align, but each must be assessed independently.[50]

However, what happens when the institution's and research participants' interests do not coincide? The door opens wide to institutional conflict of interest, as when SFU and U of O senior administrators prioritized image management and liability concerns over the protection of research

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47 For example, see Mario Brajuha & Lyle Hallowell, "Legal Intrusion and the Politics of Field Work: The Impact of the Brajuha Case" (1986), 14:4 Urban Life 454; Richard Scarce, "(No) trial (but) tribulations: When courts and ethnography conflict" (2014), 23:2 Journal of Contemporary Ethnography 123; Michael Traynor, "Countering the excessive subpoena for scholarly research" (1996), 59:3 Law and Contemporary Problems 119.

48 For article 5.1 see *TCPS2*, *supra* note 16, ch. 5. For s. 2 see Canada, Panel on Research Ethics, *Privacy and Confidentiality* (2018), online: <www.pre.ethics.gc.ca/eng/policy-politique/interpretations/privacy-privee/> [Canada, *Privacy and Confidentiality*].

49 Palys & Ivers, *supra* note 37.

50 Letter from the Office of the Vice-President, Research and Innovation, University of Toronto to the Secretariat on Responsible Conduct of Research (January 30, 2017) regarding proposed changes to *TCPS2*, online: <www.pre.ethics.gc.ca/consultations/2017/_docs/58.pdf>.

participants' rights and researchers' academic freedom. None of the respondents to Palys and Ivers' survey identified any criteria that would justify denying support to a researcher who had undergone ethics review and complied with their REB-approved research ethics protocol.

4. PRE and the Secretariat

The Secretariat under Executive Director Susan Zimmerman has strengthened *TCPS* protection of research confidentiality. Zimmerman oversaw the development of *TCPS2* in 2010, which clarified both researcher and institutional responsibilities for protecting research confidentiality. *TCPS2* clearly describes the researcher's "duty" of confidentiality, and the institution's obligation to support it:

> **Article 5.1** Researchers shall safeguard information entrusted to them and not misuse or wrongfully disclose it. Institutions shall support their researchers in maintaining promises of confidentiality.[51]

The Secretariat received a complaint about the U of O's violation of article 5.1 and, with PRE, affirmed that U of O had indeed violated that article. However, PRE stopped short of censuring the U of O, accepting its excuse that *TCPS2* needed to clarify what it means by "support". PRE then posted an interpretation on its website[52] clarifying that support meant whatever legal support is necessary for the researcher to fend off any legal threat. In workshops held at the annual national conference of the Canadian Association of Research Ethics Boards, Zimmerman affirmed that institutional responsibility.[53] She was active behind the scenes in the Boukhris case and reaffirmed institutional obligations at UQAM in the Maillé case, which contributed to UQAM's decision to change tack and support its researcher. In addition, she submitted affidavits to the Quebec Superior Court describing the vital importance of confidentiality to research in the Bruckert and Parent and Maillé cases.

However, the Secretariat's failure to reach a timely resolution of the complaint made about Kwantlen Polytechnic University's violation of *TCPS2* when it failed to support Ogden when he received a fourth subpoena gives the impression that the Secretariat and PRE are either unwilling or unable to hold institutions to account. PRE/Secretariat inaction is also noteworthy on another matter. The Supreme Court of Canada affirmed years ago that the Wigmore criteria are the appropriate measure of whether a court should privilege a particular communication. Palys and Lowman have described how researchers can take some basic measures to satisfy the

[51] *TCPS2*, *supra* note 16, ch. 5, art. 5.1.
[52] Canada, *Privacy and Confidentiality*, *supra* note 48.
[53] Susan Zimmerman, "TCPS2 Revisions" (Presentation delivered at the Annual General Meeting of the Canadian Association of Research Ethics Boards, Halifax, NS, April 28, 2017).

first three Wigmore criteria.[54] Although there may be other legal mechanisms to protect research confidentiality — such as the *Charter* protection of freedom of expression (a tactic sometimes used in the United States) or the right to privacy — currently, the Wigmore criteria ought to be at the core of any defence to be made. Why, then, do PRE and the Secretariat not make that clear in *TCPS2*?

5. The Courts

The courts have been receptive to researcher assertions of research-participant privilege. Each court that a researcher has asked to adjudicate that point has recognized such a privilege. Although their decisions vary in the level of detail they provide, it is clear that the judges involved in these cases understand the important social role that academic researchers play in pursuing their mandate of understanding all aspects of society and disseminating that information. They also understand the contributions researchers can make to the courts as expert witnesses and the justice system more broadly as consultants on important policy issues. Finally, they understand the importance of research confidentiality in acquiring information, particularly on sensitive topics and when dealing with vulnerable populations. The consistency of decisions to date is very encouraging.

Along the way, the courts have established some important principles. The Coroner in the first Ogden case understood that it was only because of participants' confidence in Ogden's pledge of confidentiality that he was able to get their cooperation and the depth of information that he did. The information would not have been available had Ogden told participants he would share the information with the Coroner if subpoenaed.

Judge Bourque in the Bruckert and Parent case did the most comprehensive application of the Wigmore criteria. In the process, she set the bar for justice personnel thinking of subpoenaing confidential research data in future. For example, she reasserted the well-established legal principle that subpoenas cannot be used for fishing expeditions. She also noted that before gaining access to privileged materials, some clear demonstration of their relevance is needed, as well as affirmation that there is no other way of getting the information through non-privileged sources. In the Bauer case, Judge Paquette added several further principles:

> (a) even anonymized data can be used to identify people if one has enough information about them;
> (b) a researcher's methods and interpretations can be scrutinized in the process of cross-examination without having access to raw data; and

[54] Ted Palys & John Lowman, "Ethical and Legal Strategies for Protecting Confidential Research Information" (2000), 15:1 Canadian Journal of Law and Society 39 [Palys & Lowman, "Strategies"].

> (c) given that researchers often play an invaluable role as expert witnesses, the courts would undermine their own search for truth if they were to order disclosures that would diminish the research that allows researchers to be expert witnesses in the first place.[55]

However, there were two problematic elements of these judgments. The first was Judge Bourque's decision in the Bruckert and Parent case to open the envelope containing the interview transcript in order to ascertain its relevance to the trial. Palys and MacAlister[56] criticize this choice because:

> (1) the chances of there being anything in the interviews useful to the Magnotta trial was effectively zero; and
> (2) it demonstrated that courts will look at materials even when there is no need to, which might well be mortifying for some participants who would never want to take a chance on even that level of disclosure.[57]

In the end, the obvious prevailed — there was nothing in the interview of use to Magnotta's prosecution. Presumably, the judge opened the envelope in order to show that her decision to privilege the interview did not come with any cost for either the defendant or the court, while simultaneously making her decision more resistant to appeal.

The second element is cautionary. Judge Pacquette made a comment in the Bauer case that raises the importance of researcher independence in a particular case. She says, "[t]he Trans PULSE study was not produced for the purposes of the present litigation".[58] Presumably, Judge Pacquette is referring to the fact that, in Maillé's case, her expert knowledge came from the very group of people who were now bringing forward the class action lawsuit and wanting "their" researcher to make a case as an expert witness. The logic here is reminiscent of that in *R. v. O'Connor*.[59] In that case, a group of women allowed access to their therapeutic records to provide the grounds for the Crown to charge Bishop O'Connor with sexual assault. However, they objected when O'Connor sought access to those same records in order to mount his defence. The court said the Crown could not have it both ways. The same principle applied to Maillé — the plaintiffs were happy to have Maillé cite their interviews when they thought it would be in their favour, but moved to quash the subpoena when the same information might be used against them. In contrast, Bauer had not gathered data at the behest of the organization that asked her to serve as an expert witness. It was an area that

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55 *Centre de lutte contre l'oppression des genres*, *supra* note 26 at paras. 51, 66, 71.

56 Palys & MacAlister, *supra* note 11.

57 *Ibid.* One would have thought Judge Bourque would have been aware of this, as her decision mentions that, notwithstanding Bruckert and Parent's solid defence of research confidences, "[a]s a result of the Search Warrant, Dr. Bruckert has been advised by one of her contacts in the sex worker community that she is regarded by this contact as having failed in her duty to uphold the promise of confidentiality in this case" at para. 109.

58 Peters, "Another case", *supra* note 24.

59 *R. v. O'Connor*, [1995] 4 S.C.R. 411 (S.C.C.).

she could provide clearly independent expertise. It is a reminder that the foundation of requests for academics to serve as expert witnesses arises in part because of their independence.

IV. How is Research Confidentiality Best Protected?

When we originally entered the national discussion of research confidentiality we took it as a given that academic research is a social good, that academic freedom is the foundation of the pursuit of knowledge, and that, in order to realize those benefits, bone fide confidential research information should be immune from legal access. It was not a question of whether the law would protect the researcher-participant relationship, but rather how researchers might best enlist law to help provide that protection.

We have argued that, while the Wigmore criteria offer researchers their best chance of protecting research participant confidentiality by having a research participant privilege recognized on a case-by-case basis, we also should consider the possibility of developing statute-based protection(s). United States examples include Certificates of Confidentiality and Privacy Certificates, and in Canada, via the *Statistics Act* that protects federal researchers and their participants at Statistics Canada.[60] The Social Sciences and Humanities Working Committee on Research Ethics (SSHWC) — a federal committee established to advise PRE and the presidents of the granting agencies on how to improve the *TCPS* to better serve Canada's social sciences and humanities research communities — also encouraged PRE to look further into the development of statute-based protections. SSHWC gave five justifications for the creation of a Canadian research shield law of some sort:

- Researchers who prioritize ethics must be prepared to defy the law, and face possible incarceration, for their ethical commitment. A statute-based privilege would allow ethics-first researchers to have their obligations protected in law.
- Researchers who would prioritize law must refrain from asking questions that would place participants at risk if their responses or identities were disclosed, because gathering information that could harm participants knowing one would disclose it would be exploitative. A statute-based privilege would allow law-first researchers to gather information on sensitive topics without endangering participants through possibility of disclosure.
- REBs have a conflict of interest: providing effective oversight requires documentation, but documentation creates paper trails that can endanger research participants. A statute-based

[60] Palys & Lowman, "Strategies", *supra* note 54.

privilege would allow REBs to provide effective oversight by ensuring that any documentation cannot be subject to disclosure.

- A court may call upon researchers acting as expert witnesses to disclose identifiable information. A statute-based privilege would allow researchers to act as expert witnesses knowing that the court cannot request identifiable information, allowing them to assist the court knowing the court will respect their ethical commitments.
- When the State can order disclosure, it compromises the autonomy of research. A statute-based privilege would allow researchers to contribute knowledge about some of society's most controversial and pressing issues without concern that the state will harass research participants.[61]

To this list of justifications, we have added two others.[62]

First, although every Canadian case that has gone to a hearing thus far has resulted in the recognition of research-participant privilege, there are reminders of the fragility of that protection. The central problem with asserting research-participant privilege through the common law is that the court effectively makes law after the fact, depending on which legal scenario resulted in the subpoena. However, researchers must make their pledges of confidentiality to participants well before that scenario arises, which can leave the ethical researcher facing the prospect of jail for living up to his/her ethical commitments. The US Supreme Court commented on that very issue in *Jaffee v. Redmond*[63] when considering whether to recognize a therapist-client privilege:

> We reject the balancing component of the privilege implemented by that court and a small number of States. Making the promise of confidentiality contingent upon a trial judge's later evaluation of the relative importance of the patient's interest in privacy and the evidentiary need for disclosure would eviscerate the effectiveness of the privilege. As we explained in *Upjohn,* if the purpose of the privilege is to be served, the participants in the confidential conversation "must be able to predict with some degree of certainty whether particular discussions will be protected. An uncertain privilege, or one which purports to be certain but results in widely varying applications by the courts, is little better than no privilege at all".[64]

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61 Social Sciences and Humanities Research Ethics Special Working Committee, "A Briefing Note to PRE Regarding Statute-Based Protections for Research Participant Privacy and Confidentiality", *Simon Fraser University* (June 10, 2005), online: < www.sfu.ca/~palys/SSHWC-CCBriefingNote-2005-Final.pdf > [SSHWC, "Briefing Note"]; *SSHWC Recommendations Regarding Privacy and Confidentiality*, *Panel on Research Ethics* (February 2008), online: < www.pre.ethics.gc.ca/eng/archives/policy-politique/reports-rapports/sshwc-ctsh/#Back15 > .

62 Ted Palys & John Lowman, "Protecting Research Confidentiality: Towards a Research-Participant Shield Law" (2006), 21:1 Canadian Journal of Law and Society 163.

63 *Jaffee v. Redmond*, 518 U.S. 1 (1996).

We are concerned that a lack of statute-based protection makes researchers and research participants vulnerable to prosecutors and attorneys who feel they have nothing to lose by requesting information from researchers who hold information about individuals who have some connection to criminal or suspicious activity, or who have information from individuals who later become litigants. In the absence of a research shield law, attorneys can raise the stakes by requesting a subpoena or court order, knowing that the onus to demonstrate why the court should not order disclosure of information will fall on the researcher. In the United States, appeals courts have shown they are not prepared to countenance overzealous subpoenas that amount to researcher harassment,[65] but the courts have not had occasion to rule on that issue in Canada.

Second, how do researchers address the problems that digital technologies pose to research confidentiality? Bourgeoning digital technologies have created a virtual candy store of delights to facilitate different aspects of research.[66] Yet, the Snowden revelations and the development of a surveillance economy[67] have shown us that digital means hackable. Paradoxically, researchers who seek to be state-of-the-art technologically may simultaneously endanger their participants because of the insecurities that seem inherent to digital files and networks.[68] A statute-based privilege would not negate that threat but would probably ensure that any information obtained by such means would be inadmissible in court.

There would appear to be considerable support for the development of statute-based protections within the broader research community. In response to SSHWC's briefing paper that encouraged PRE to consider lobbying for the development of statute-based protections, the presidents of the three Canadian granting agencies sought input from scholarly associations in Canada. They received three submissions — from the Canadian Psychological Association, Canadian Law and Society Association, and the Canadian Historical Association. The first two thoroughly supported developing statutory research confidentiality protections, while the third saw both positives and negatives.[69] More recently, a national survey of Research Ethics Board Chairs and ethics administrators included a question about whether the respondent would support the development of statute-

64 *Ibid.* at paras. 17-18.

65 See Palys & Lowman, *Protecting*, *supra* note 6; see also Cecil & Wetherington, *supra* note 35.

66 Ted Palys & Chris Atchison, "Obstacles and Opportunities: Qualitative Research in the Digital Age" (2012), 11:4 International Journal for Qualitative Methods 352.

67 Shoshana Zuboff, "Big Other: Surveillance Capitalism and the Prospects of an Information Civilization" (2015), 30:1 Journal of Information Technology 75.

68 Ted Palys, "The Cost of Free: Implications of Contemporary Internet Governance for the Future of Criminological Research" (Paper delivered at the annual meetings of the Western Society of Criminology, Vancouver, BC, 2016) speaking notes online: < www.sfu.ca/~palys/WSC-2016-TheCostOfFree.pdf > .

69 See Palys & Lowman, *Protecting*, *supra* note 7.

based protections for research confidentiality in Canada. In response, 40 out of 73 participants (54.8%) said they *would* support such an initiative, while 32 (43.8%) said they *may* support such an initiative, depending on what form it takes. Only one (1.4%) respondent dismissed statute-based protections for Canadian researchers as a bad idea.[70]

SSHWC's briefing paper concluded by noting that,

> [i]f PRE decides to recommend to the Presidents of the Granting Councils that they pursue and promote the development of made-in-Canada Confidentiality Certificates, there will be much work required to make them a reality. Certainly an examination and discussion awaits regarding how they will be constructed, who will administer them, and how they will fit into Canada's existing evidentiary framework.[71]

Some work along those lines has begun.[72] We encourage the continuation of that discussion.

[70] Aaren Ivers, "*Without trust, research is impossible*": *Administrative inertia in addressing legal threats to research confidentiality* (MA Thesis, Simon Fraser University School of Criminology, 2017) at 40-45 [unpublished], online: < http://summit.sfu.ca/item/17470 > .

[71] SSHWC, "Briefing Note", *supra* note 61.

[72] Palys, Turk & Lowman, *supra* note 35.