"Hope for the Best and Plan for the Worst:" The State of Confidentiality Protection Policies in Canada[1]

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A few years ago, I was honoured to be a part of SSHWC -- the Social Sciences and Humanities Working Committee on research ethics -- which was one of numerous committees put together to advise PRE and the Presidents of the granting agencies on potential changes to incorporate into what was then an envisioned TCPS2.

One of the many issues we addressed was confidentiality, and one of our priorities was to try and ensure that what happened at my university couldn't happen again. For those of you who aren't familiar with that story, the short version is that the university loved everything about Russel Ogden's research until a subpoena arrived, at which point they promptly abandoned him and his research participants to their own devices. Although the university eventually would apologize to Ogden for its moral lapse and laud his courage for following an ethical course of action, my colleagues and I on SSHWC hoped TCPS2 would clarify not only researchers' obligations to protect research confidences in the face of legal challenge by a third party, but the role of institutions in that defense as well.[2]

It was thus gratifying when TCPS2 came out to see Article 5.1, which stated not only that researchers shall safeguard the information entrusted to them and resist threats to research confidences, but also that "Institutions shall [sic] support their researchers in maintaining promises of confidentiality." Not SHOULD, mind you – which the TCPS explains denotes encouragement but remains discretionary – but SHALL, which denotes a requirement.

But then along came the Bruckert/Parent case at OttawaU, and what did OttawaU do? Exactly the same as SFU had done. Were it not for the intervention of Jim Turk and CAUT, who Barbara[3] and I agree are the real heroes here, this case could have gone in a very different direction with a very different outcome.

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[1] These are speaking notes for an invited plenary talk to delegates at the annual meetings of the Canadian Association of Research Ethics Boards (CAREB) held in Halifax, NS, on 28 April 2017. I thank my colleagues John Lowman and Chris Atchison for our discussions on these issues, and Aaren Ivers, a graduate student in the School of Criminology at SFU with whom I collaborated on the national survey described herein. I also acknowledge funding assistance from the SSHRC Small Grants program that facilitated that research.

[2] The story of the Ogden subpoena and its aftermath is recounted in T. Palys & J. Lowman (2014). *Protecting Research Confidentiality: What Happens When Law and Ethics Collide*. Toronto: Lorimer.

[3] This refers to Barbara Graves of the University of Ottawa, Chair of the OttawaU behavioral REB, who, along with Jim Turk, were co-panelists for this presentation.

In response to a complaint that OttawaU had violated its MOU with the granting agencies by violating the TCPS by not living up to Article 5.1, PRE issued an interpretation that put OttawaU and all other institutions across the country on notice that "support" meant legal representation and not just a pat on the back.[4] The interpretation also encouraged, but did not require, institutions to develop policies in which they articulated how they would implement their responsibilities under Article 5.1.

> Institutions under whose auspices or within whose jurisdiction such research is being conducted should [sic] 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.[5]

This advice is consistent with the US literature on threats to research confidentiality that suggests the more prepared you are and the more researchers know what to do when and if a subpoena comes, the better it is for everyone. But two years after the interpretation came out, my impression was that very few if any institutions had developed policies of this sort. I thought it important to determine more systematically just what the state of policy development was, in the hope that doing so would help identify best practices and promote discussion about how best to ensure research participant confidentiality was both respected and defended.

With the assistance of a small SSHRC grant, graduate student Aaren Ivers and I designed a multi-method study to find out. We started off by creating a list of every institution in the country that had at least one MOU with a granting agency, which means they are bound to adhere to the TCPS. We then approached 207 REB Chairs in 161 English language institutions -- or as close as we could get[6] -- and asked them to participate in a brief survey. We also asked them to indicate if they were willing to be interviewed afterward, and supplemented that information with web searches trying to find whatever policies might be retrievable online.

In the end we had 73 survey responses from 63 different institutions (which is about a third of those approached), and did 20 interviews with those who indicated an interest in speaking with us further.

The bottom line? Two years after the interpretation came out, there is exactly one policy that meets what I understand the requirements of a policy to be, i.e., not WHETHER the researcher will be supported, but HOW and BY WHOM. The one policy is at McGill, where they have a

[4] See http://www.ethics.gc.ca/eng/policy-politique/interpretations/privacy-privee/, particularly Section 2.
[5] Ibid. See Section 2E.
[6] While most research institutions have web pages devoted to ethics policies and the Offices of Research Ethics (OREs) and Research Ethics Boards (REBs) that implement them, we were surprised to find out just how many were almost secretive about the Boards and their membership, which sometimes even continued when we contacted them by email to ask the name of their REB Chair.

process in place that avoids *ad hoc*ery, and outlines some of the various ways that support might be given, with the intention of the discussion being to determine not WHETHER support will be given, but on HOW the institution might best support the researcher(s) in his/her/their defense of the confidentiality of the participants.[7]

So what sorts of impediments were getting in the way of the remaining 72 (98.6%) of our survey sample developing a policy? From what we've seen thus far, there appear to be four main reasons:

1. The interpretation says "should" and not "shall." This allows institutions to dismiss, procrastinate and thereby avoid what university administrators like to avoid, i.e., policies that incur liability and limit their discretion.

2. A second reason given was that creating a policy was low priority because actual legal cases are so rare. And they are indeed rare. Almost twenty years passed between the first case (Ogden) and the second (Bruckert/Parent). However, we now have 3 cases in relatively quick succession -- the Bruckert/Parent case from U of Ottawa; the Maillé case from UQAM; and as we learned recently, the Bauer case from U of Western Ontario.[8] Is this just a temporary spike? Or a harbinger of things to come? And is rarity a reasonable excuse when the potential costs to participants are so high? Or does that make it more like earthquake preparedness, i.e., where one hopes for the best but nonetheless ensures a plan is in place should that event happen?

3. Other respondents justified their lack of policy by noting, "we only do minimal risk." While this excuse might have been understandable after the first two cases that involved researchers speaking with law breakers, the Maillé case was seen by several of our respondents as a "game changer." Who could have predicted that interviews with

[7] I had originally stated at the CAREB meetings that there were no policies that met the criteria, thinking that McGill's policy outlined a process, but without a guarantee of support. An individual from McGill approached me after I gave my talk and suggested I misunderstood the policy. In her view, the question of WHETHER a researcher would be supported legally was not at issue, and that the process McGill's policy outlines is simply to update key individuals about what is happening and to assess what the researchers' needs are to most effectively combat the legal challenge. In subsequent correspondence with authorities at McGill I have been assured that her characterization is correct. The policy is available online at https://www.mcgill.ca/research/files/research/institutional_support_to_researchers_in_maintaining_promises_of_confidentiality_.pdf

[8] The Bruckert/Parent case is described in detail in Palys & Lowman's *Protecting Research Confidentiality* (see footnote 2). For a brief description of the Maillé case, see D. Peters (18 January 2017). Quebec researcher in legal fight over research confidentiality. *University Affairs* online at http://www.universityaffairs.ca/news/news-article/quebec-researcher-legal-fight-research-confidentiality/. For a brief description of the Bauer case see D. Peters (24 April 2017). Another case involving research data confidentiality hits the courts. *University Affairs* online at http://www.universityaffairs.ca/news/news-article/another-case-involving-research-data-confidentiality-hits-courts/.

people who live around wind farms would result in a subpoena further down the road? Bauer's case -- which involved a quantitative data base that was created from a national survey -- also came as a surprise to her. One lesson that she asked me to share with you when I spoke with her earlier this week was her realization that cases can come from anywhere, and not simply from studies about lawbreakers.

4. A fourth reason, which was especially common among but not exclusive to smaller institutions, was "we just don't have the expertise or resources to write one." These institutions were looking to see what other institutions did, and also hoped for more guidance from PRE and the Secretariat.

So, where does all this take us to? What can be done? For me this raises more questions, three of which I'll share today:

1. Should "should" become "shall"? PRE and the Secretariat have tried to avoid being too prescriptive, for the very good reason of wanting to tread lightly when it comes to issues of university autonomy, but is this a situation where making a policy a requirement and possibly sketching out a set of policy criteria or even offering a template might be warranted?

2. Some participants expressed concern about the costs associated with providing a defense, but why should any one institution be burdened with the costs of a defence when all of us benefit or lose by the decisions? Are there vehicles like insurance or a common fund that could be created to spread the risk?

3. Are there other ways to deal with this issue? One of the things we asked about in the survey was whether people would support the idea of developing statute-based protections such as the protections that Statistics Canada researchers and their participants have via the *Statistics Act*, or that researchers and participants in the US have in some situations through confidentiality certificates or privacy certificates? There was resounding support for that idea among our survey sample -- only 1 person out of 73 said "no." That would certainly be a longer term project, and certainly we should be careful what we wish for, but is this an idea whose time has come?

A primary reason for doing the study was to promote discussion on these issues, and I appreciated the opportunity to participate in this forum with my colleagues Jim Turk and Barbara Graves and this audience, and want to finish simply by thanking Lori Walker for helping make that possible.