

**Humber Research Ethics Board (REB) Bulletin No 4 /2019**

**This informational bulletin is part of the Humber REB's public awareness initiatives.**

**November 2019**

**Do you have an absolute guarantee of confidentiality when you participate in a research project?**

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**Examining the Boundaries of Researcher-Participant Confidentiality**

To gain the trust and confidence of research participants, researchers will normally offer assurances that the information to be collected will be kept confidential. A consent form is essential to document this assurance, and this form will be reviewed carefully by the REB. As a rule, the more sensitive the information to be collected from research participants, the more likely it is that the REB will insist on seeing strong protocols for the protection of this information. For example, the REB will likely insist on stronger protection protocols where the information to be collected relates to health information or is connected with behaviour on the part of research participants that may be deemed to be in violation of the law.<sup>1</sup>

The REB also ensures that no demonstrable potential for adverse effects exists. Where the potential for such effects is detected, ethics approval may be withheld until the researcher submits an appropriate mitigation plan.

Once ethics approval has been granted (and except in cases where the REB has made its approval conditional on additional monitoring), the matter will fall outside the purview of the REB. However, during the execution of the research and even after its completion, matters may arise that test the ability of the researcher to make good on the assurances made to research participants regarding the confidentiality of their data. Examples relate to research disclosure requests by law enforcement or by other persons through the court system.

In applying what is known in Canadian jurisprudence as the “**Wigmore**” criteria, the Supreme Court of Canada (SCC) has held that a promise of confidentiality will be respected by a court if:

- (a) the communication originates in a confidence that the identity of the informant will not be disclosed;

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<sup>1</sup> For example, research into the socio-economic factors underlying juvenile delinquency would require the REB to insist upon strong data protection protocols if research participants include juveniles who are active members of criminal gangs.

- (b) the confidence is essential to the relationship in which the communication arises;
- (c) the relationship is one that should be vigorously fostered in the public good; and
- (d) the public interest in protecting the identity of the informant from disclosure outweighs the public interest in getting at the truth.<sup>2</sup>

Increasingly, the boundaries of the ability of researchers to maintain researcher-participant confidentiality are being tested. A request for the disclosure of research data was most recently considered by the Superior Court of Quebec in the case of *Rivard c. Éoliennes de l'Érable* (the “Maillé” case)<sup>3</sup>.

In 2010, Marie-Evé Maillé collected research data from residents of a town in Quebec for the purposes of completing her research thesis. The focus of her thesis was social cohesion between two towns that complained of negative environmental impacts arising from the activities of a large corporation. Maillé completed her PhD studies and published her research thesis in 2012. That year, the residents of the two towns commenced a class action lawsuit against the corporation. Maillé was asked to testify as an expert witness on behalf of the plaintiffs. This request led to a judge of the Superior Court of Quebec ordering her to produce to the defendant all of her research findings. The problem this order presented was that Maillé had assured her research participants of confidentiality and her compliance with the court order would breach this assurance. Fortunately, the judge later withdrew his earlier order for Maillé to produce the research data.

The judge ruled that all four of the *Wigmore* criteria had been met. Notably, the judge found that a clear promise of confidentiality had been given by the researcher and that the need to support scientific research was a valid societal objective, irrespective of whether or not the research participants were in a vulnerable position. These findings are significant in that they highlight the court’s recognition that researchers may only be able to conduct research effectively if participants can develop a legitimate expectation that data which they provide will not be later used in a manner adverse to their interests.

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<sup>2</sup> R. v. National Post, [2010] 1 SCR 477

<sup>3</sup> 2017 QCCS 2259

The need to protect, as far as possible, the integrity of the research process, was highlighted in even clearer terms in the earlier case of *Parent c. R.*<sup>4</sup> In this case, two researchers sought a declaration from the court that research materials seized by the police pursuant to a search warrant were protected under researcher–participant privilege. The judge applied the Wigmore framework and ruled in favour of the researchers. Underlying the decision were the important findings of the judge that:

- (i) The granting and maintenance of confidentiality were integral to the research project.
- (ii) The assurance of confidentiality to research participants was an essential part of the approval of the ethics application by the REB at the University of Ottawa, and the funding approval.
- (iii) The *Tri-Council Policy Statement* supports the researchers’ position that researcher-participant relationships ought to be diligently fostered in the interest of the community; and
- (iv) The evidence demonstrated that the public interest in respecting the promise of confidentiality was high.
- (v) While the interest of society in the investigation of serious crimes was also high, the probative value of the specific information being sought was, at best, minimal and marginal.

Neither of these two cases supports a broad assertion that claims to researcher-participant confidentiality will always be upheld, given that the **Wigmore** framework is to be applied on a case-by-case basis. What they do demonstrate however, is that in the presence of competing interests, researcher-participant confidentiality will likely only be displaced where the researcher’s assurance of confidentiality was not itself integral to the research process and / or where a competing public interest in having access to the information is strong enough to predominate.

There is a best practice that emerges from this discussion for both researchers and REBs. Researchers should act with the utmost good faith towards research participants and in light of potential legal limitations, refrain from offering absolute guarantees with respect to the

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<sup>4</sup> 2014 QCCS 132

maintenance of confidentiality. The integrity of the research process may be imperilled if these guarantees cannot be upheld.

Future research participants may be reticent to engage in research activities, especially those dealing with highly sensitive issues. Furthermore, researchers may face legal jeopardy vis a vis research participants if, ultimately, disclosure has to be made.

**At the recruitment stage, researchers should, therefore, make it clear to research participants that, while the researcher will take every practical step to ensure the confidentiality of the data to be collected, the researcher may have to make disclosures in compliance with lawful demands of law enforcement or in compliance with the orders of a court.**

It is not inconceivable that the REB could also face legal jeopardy where ethics clearance was granted without adequately insisting that, as a part of the informed consent process, research participants should have been advised of possible limitations to confidentiality. For this reason, the REB should insist on this awareness being brought to the attention of research participants in the consent form.

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