

Reconciling the Law and Ethics of Research Confidentiality¹

Ted Palys & John Lowman
Simon Fraser University

Research Confidentiality

- A core ethical principle
- A fundamental element of trust, rapport
- Often essential for valid data
- Often easily safeguarded by
 - gathering data anonymously
 - using pseudonyms from the outset
 - anonymizing transcriptions ASAP
- But can't always anonymize; challenges can arise

Challenges from Third Parties

- In the U.S., these challenges arose in two distinctive waves and involved third parties seeking to co-opt researchers
 1. as witness for the prosecution
 - Disciplinary areas affected have included Criminology, Health Studies, Political Science, Sociology, Sexology
 2. in the crossfire of civil litigation
 - Disciplines/areas affected have included Business Administration/Organizational Behaviour, Health (particularly epidemiological, clinical, biomedical research), Anthropology.

Conflicts of Ethics and Law

- Although we hope that ethics and law will always coincide – because ideally we want to be both ethical *and* legal -- these challenges create the possibility of a divergence of ethics and law.
- The *TCPS* recognizes this when it states:

[L]egal and ethical approaches to issues may lead to different conclusions. (p. i-8)

¹ Paper presented at a national conference of the National Council on Ethics in Human Research (NCEHR) entitled "Privacy Issues in Human Research." Aylmer, Québec; March 6-7, 2004. This manuscript is a combination of the Power Point slides and presenter's notes.

Reconciling Law and Ethics

- In the United States, researchers resolved this divergence through a combination of
 - Being prepared to go to jail if it came to that
 - Resisting subpoenas every step of the way whenever identifiable information is sought
 - Calling for statutory protections that would effectively protect research participants

The Canadian Experience

- Russel Ogden's experience was for the most part very much in keeping with the best of those traditions
 - Shared his information in a general way with the courts and interested parties (e.g., Senate)
 - Resisted subpoena vigorously and used the best available defence (Wigmore) to protect anonymity of his participants; and
 - Outcome: Coroner recognized privilege and protected his research participants
- It was the University and REB who initially were out of step:
 - Apparently did not believe there was a defence to be made
 - Despite urgings, never did show leadership in advancing the case for a statutory privilege to end the uncertainty; and
 - Believed "no more Ogdens" would be achieved by "no more confidentiality"

Law as Constraining

- Underlying the university's initial response was a view of law as something to run from and that can only constrain us, i.e., places emphasis on "understanding the limitations" that are placed on us by law
- This creates more problems than it solves by making us targets, sitting ducks
 - Compare Ogden Subpoena #1 to #2

Law as Enabling

- The TCPS gets it right when it says,
[A]lthough ethical approaches cannot preempt the application of the law, they may well affect its future development or deal with situations beyond the scope of the law." (p. i-8)
- Embedded in that view is an approach that understands law not as an enemy, but as an ally, and sees it as something to be used in the service of ethics.

The Wigmore Criteria

- In the short term, using law means ensuring that our research is designed in such a way as to maximize our ability to assert privilege
- Done via Wigmore, as Ogden showed us. The criteria are:
 - **the communications must originate in a *confidence* that they will not be disclosed.**
 - **this element of *confidentiality must be essential to the full and satisfactory maintenance of the relation between the parties.***
 - **the *relation* must be one which in the opinion of the community ought to be sedulously *fostered.***
 - **the *injury* that would inure to the relation by the disclosure of the communications must be *greater than the benefit* thereby gained for the correct disposal of litigation.**

Statutory Protections

- In the long term, it means resolving the conflict between ethics and law by developing statutory protections that reflect our ethical obligations to research participants
- Three approaches to such protections can be distinguished:
 1. **Global Statutory Protection**
 2. **Case-by-Case Consideration**
 3. **Performance Criteria**

1. Global Statutory Protection

- Example: *Statistics Act*
- Protects those who take part in Statistics Canada research, especially the census
- An example of protection lodged in the authority of a highly centralized institution
- Never been challenged, but theoretically is open to it via *Charter* challenge

2. Case-by-Case Consideration

- Example: **Confidentiality Certificates**
- Administered by the US National Institutes of Health (NIH) and other Health and Human Services agencies
- Available for sensitive “health” research in which confidentiality is required in order to gather valid identifiable data.
- Examples of “sensitive” information include information relating to:

- sexual attitudes, preferences, or practices
 - the use of alcohol, drugs, or other addictive products
 - illegal conduct
 - information that, if released, could reasonably be damaging to an individual's financial standing, employability, or reputation within the community.
 - information that would normally be recorded in a patient's medical record, and the disclosure of which could reasonably lead to social stigmatization or discrimination.
 - information pertaining to an individual's psychological well being or mental health.
 - genetic information.
- The receipt of certification allows one to guarantee confidently that:

Research or statistical information identifiable to a private person shall be immune from legal process, and shall only be admitted as evidence or used for any purpose in any action, suit, or other judicial, legislative, or administrative proceeding with the written consent of the individual to whom the data pertains.

- Impervious to legal challenge. Its case-by-case basis of consideration is its legal strength

3. Performance Criteria

- Example: **Privacy Certificates**
- Offered through the US National Institute of Justice
- Project-specific; must meet objectives
- More researcher and project-driven, defined
- Statement of steps that will be taken to ensure confidentiality requirements will be met
- Once approved, plan is protected by statute
- The researcher “shall not use or reveal any research or statistical information furnished by any person and identifiable to a private person for other than research or statistical purposes.”
- Potentially severe penalties for violating this provision.
- Identifiable information is immune from legal process and cannot be admitted as evidence "in any action, suit or other judicial, legislative, or administrative proceedings."

Made in Canada Protections?

- CAUT has taken a leading role in promoting their development, including communication with those who developed Confidentiality Certificates in the US
- The granting councils are “looking into it” and have been soliciting input from the disciplinary associations as to the need for such protections

- It's still early in the process, but here are some criteria that should be kept in mind as the process evolves:

Criteria for Prospective Protections

1. Must be a research *participant's* privilege, not a researcher's

- Nothing special about researchers beyond need for freedom from harassment, and a recognition of the value of academic freedom for generating knowledge
- Consistent with other kinds of privilege, e.g., it's the client's, not the lawyer's. Consistent also with US jurisprudence that zealously safeguards research participants
- The danger in the situation comes from us and our presence in their lives
- It's their right to waive

2. Must be considered on a case-by-case basis

- Consistent with the logic of ethics review
- Is what will make it legally fortified
- An extension of the logic of the Wigmore test (criterion two: confidentiality must be essential to that particular interaction)
- Any court challenge would look at whether there was a considered balancing of social value. Court will need to feel assured that legitimate authority assented; within the norms of the institution.

3. Must be administered in a context that values academic freedom

- Case-by-case decisions invite the opportunity for agenda-setting
- Must be free of institutional and governmental conflicts of interest to ensure that critical research is possible and protected
- Must inhibit meddling; "social value" a minefield
- Glad to see that CAUT – an organization that clearly advocates for academic freedom -- is playing a leadership role in advancing the development of confidentiality protections

4. Must be available for both funded and un-funded research

- Compare Confidentiality Certificates with Privacy Certificates
- More consistent with implementation decisions re the TCPS to include both funded and non-funded research, i.e., not just funded
- If privilege lies with the participant, they, and our ethical obligations to them, are the same whether funded or not