

Navigating Legal Waters with an Ethical Compass:

The Ethics and Law of Research Confidentiality

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Ethics and Law

- We were asked to consider "the general issues of confidentiality and the increasingly legalistic obligations of social researchers"
- A twofold issue
 - The external world and the extent to which researchers require legal knowledge in order to negotiate it; and
 - The university as a social institution and how it negotiates conflicts between ethics and law
- Our research training, disciplinary codes and university policies commit us to maintaining the highest ethical standards
- As citizens we believe in the rule of law and an obligation to honour it
- Research confidentiality is an area where those two obligations *can* conflict

Russel Ogden and SFU

- An example: Russel Ogden does his MA thesis on assisted suicide among persons with HIV/AIDS
- Clearly an area where research can make a contribution to society:
 - Controversial area
 - Little was known; begs for empirical data
 - Opportunity to contribute to social policy debate and the development of policy

- Just as clearly an example of why confidentiality is considered a core ethical principle:
 - Integral to the gathering of valid data
 - The information is created for our and society's benefit, with no immediate benefit to participant
 - Huge potential negative consequences to participant if the confidence is violated; their fate in our hands
- The only reason the information will exist is because of the pledge of confidentiality and trust that unlocks it
- Sought by media, Senate committee
- SFU basks in the attention
- Also captures the interest of Coroner
- Ogden becomes the first researcher in Canada to be subpoenaed and asked to divulge confidential research information to a court
- SFU effectively abandons Ogden, apparently because of worries about image and liability
- SFU's VP-Research asserts "Law of the Land" doctrine:
 - The only law that counts is statute
 - No university can countenance a researcher defying a legal order
 - Therefore there can be no confidentiality
- SFU runs from law and limits confidentiality
- Ogden embraces law and asserts privilege

SFU is Encouraged to Reconsider

- Two independent assessments in quick succession lambaste Simon Fraser University for its failure to stand with Ogden in his defense of research participants and the research enterprise. The first is in the context of a suit that Ogden had brought against the university for what he characterized as a breach of contract on the part of the university.

“The vague statements of personal support as expressed by the president of the University, Dr. Stubbs, and the dean of Graduate Studies, Dr. Clayman, sound hollow and timid when compared with the opportunity they had as leaders of the University, to promote the demonstrated value of academic freedom and academic privilege as evidenced in this case. To set aside this opportunity because of fear that if they were to financially support Ogden by paying his legal fees in this context, some people might misapprehend that they were in favour of euthanasia, demonstrates a surprising lack of courage.” (Judge Daniel Steinberg in *Ogden v SFU*)

- While waiting for the Steinberg decision, President Jack Blaney of SFU had established an independent panel to reconsider the university administration's decision-making in the Ogden case. They, too, chastised the university for passing on such a clear opportunity to assert the importance of its social mission:

“Challenges to academic freedom can come both from within and without the university. A

university can guarantee to protect academic freedom against actions inside the institution that are within its legal and moral jurisdiction. It can, of course, give no such guarantee about threats to academic freedom that come from outside the university. But a university has the obligation to try to protect this freedom from such external threats and challenges. If universities do not take on this obligation to protect such a basic institutional right, who will?" (Blomley & Davis Report)

- President Jack Blaney of SFU eventually accepted the recommendations of Professors Blomley and Davis and (a) apologized to Ogden, stating in the process that his behaviour was ethical and exemplary; (b) reimbursed Ogden for his legal and other expenses incurred in the defense of his research participants; and (3) made it clear that, in future, if anything similar were to happen, the university would be there to defend research participants, the research enterprise, and academic freedom.

Russel Ogden and Exeter

- Ogden went to Great Britain to pursue PhD studies at Exeter University, and, after his experiences at SFU, was understandably cautious about assuming the university would be there to defend research confidentiality. He asked for written assurance and received the following:

"In the knowledge of the applicant's previous experience of the need to actively uphold the commitments to confidentiality given to research subjects, the members of the Committee express their personal support for the researcher in continuing to meet such commitments. They recognise that entry into commitments of this kind is integral to the pursuit of truth through sociological research, and accept the obligation to support and sustain those who do so." (Exeter Sociology Dept. Ethics Committee)

- On the basis of these assurances, Ogden began his research and had interviewed close to 100 persons who had assisted in or observed suicides when various events gave him concern about the university's commitment. When a research participant wrote to the university asking for specifics, s/he received the following:

"In the knowledge of the applicant's previous experience of the need to actively uphold the commitments to confidentiality given to research subjects, the members of the Committee express their personal support for the researcher in continuing to meet such commitments. They recognise that entry into commitments of this kind is integral to the pursuit of truth through sociological research, and accept the obligation to support and sustain those who do so." (Exeter University)

- A sentence had mysteriously vanished; what began as a commitment had become a platitude
- Participants are confident of Ogden, but what of Exeter? Conflict prevails. The research is in turmoil and Ogden's PhD disintegrates
- Grievance filed
- "The Visitor" – Britain's Lord Chancellor, representing the Queen -- intervenes and concludes Ogden's supervision was incompetent and ethics mismanaged by his committee.

Law as Constraining

- Underlying both SFU's initial response and that of Exeter is a particular view of law as static, monolithic and constraining
- All we can do is "understand the limitations" that law bestows upon us
- It involves the absolute subjugation of ethics to law, dispenses with confidentiality and replaces it with a sole focus on informed consent
- Places a low value on the research enterprise, apparently believing:
 - cannot compete with other societal interests of the sort that are represented in legal proceedings; or
 - is simply not worth defending
- This path takes us to the end of academic freedom, and either an exploitative *caveat emptor* ethic or the inability of the university to fulfil its social mandate

Law as Enabling

- Another view of law sees it not as an enemy, but as an ally to be used in the service of ethics
- SFU has now officially recognized that view; begins by apologizing to Ogden
- Researchers at SFU can follow an ethics-first *or* law-first approach; either way the university has established as policy that it will fight for research participants
- Canada's federal ethics code has also endorsed the position.
- Regarding ethics and law, it notes:

"[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 or deal with situations beyond the scope of the law." (TCPS, p. i-8)

- Researchers are not above the law, but it is only by acting ethically and challenging the law that we have any hope of affecting its future development so that law and ethics coincide
- One need look no further than the example you in the U.S. set for the rest of us – your resistance to the wave of subpoenas that began in the 1960s and 1970s was part of what produced the statutory protections we in Canada envy

Is the Work Done?

- No...
 - still much research not covered by the statute-based protections you have
 - U.S. researchers have not yet embraced the Wigmore criteria as a way to prepare for those occasions where ethics and law conflict
 - The law-of-the-land approach is active in the U.S., but results in either
 - Inability of the university to achieve its mandate; or
 - An exploitative approach that makes *caveat emptor* the new ethic

Do Researchers Need to Know Law?

- Yes ...
 - because it is your ally, and U.S. courts have shown they value research and will protect research participants
 - because understanding the logic of the Wigmore criteria will help you to assert privilege when you are not eligible for CC/PCs
 - but understanding your ethical obligations is far more important and, ironically, the only way to change law