

The New Brunswick Declaration of Research Ethics: A Simple and Radical Perspective

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Each year Canada spends an estimated \$35 million to maintain a research ethics oversight system (van den Hoonaard 2011), but in the eyes of many researchers not much benefit accrues to social science researchers, research participants, and even to the ethics regime itself. Thus, uncertainty and doubt mark Canadian sociologists as they traverse the unpredictable waters of research ethics review created by the passage of Canada's *Tri-Council Policy Statement on Research Involving Humans* (aka *TCPS*) (Medical Research Council et al. 1998) some 16 years ago. The *TCPS* was subsequently revised as *TCPS 2* in 2010. Worldwide, since 2000, almost 200 scholarly publications including books (Schrag 2010; van den Hoonaard 2011; Stark 2012), book chapters, and articles have recorded the troubled histories of scholars with ethics regimes and ethics committees.

In this climate of the disadvantages faced by the social sciences, researchers at St. Thomas University and the University of New Brunswick felt emboldened to organize the "Ethics Rupture" Summit (with a grant from the Social Sciences and Humanities Research Council) in October 2012. With 33 scholars attending from around the world, the Summit outlined the broad swath of problems with the research ethics process which are now quite universal.¹ The development of the 2012 Declaration on Research Ethics, Integrity and Governance ("the Dec-

1. The reader can find more detailed discussions about the "Ethics Rupture" Summit and the Declaration in van den Hoonaard (2013b and 2013c).

laration”) grew out of a near-two decade historical process marked by the disappointment and frustration of social science researchers with the implementation and effects of ethics policies not only internationally but also in Canada.

THE CANADIAN APPROACH CRITICAL OF RESEARCH-ETHICS REVIEW

The scholarly community in Canada has not been silent about how the research ethics review system has handicapped research. Possibly the earliest piece critical of the emerging ethics regime in Canada was Linda Christiansen-Ruffman’s “Points” (1998) which she originally presented in 1997 at the annual meetings of the Canadian Sociology and Anthropology Association (now the Canadian Sociological Association), along with Gail Pool’s article in the Association’s newsletter, *Society/Société* (1998). The formal implementation of Canada’s ethics review regime in 2000 initiated a slew of objections based on both epistemological (e.g., Mueller et al. 2002; van den Hoonaard 2001) and empirical grounds (e.g., Palys and Lowman 2001; van den Hoonaard 2002).

Several critical themes emerged in those published accounts, particularly the inappropriateness of the biomedical basis of the research ethics regime for sociology, the problems created by mandatory written and signed consent, and research ethics review as a moral panic and as part of an audit culture. These themes also permeated the next decades of scholarly publishing as scholars began to note the influence of bureaucracy on research ethics review. For example, Kevin Haggerty (2004) wrote on the “ethics creep” of the ethics bureaucracy, a concept which has become frequently cited in the field of studies on research ethics review; it spoke to the consequences of the ethics review bureaucracy intent on expanding its influence. According to Ron Iphofen (2009), research governance has so enveloped the research ethics review process that rigidity, conservatism, risk avoidance, and safeguarding against liability have become the foci of its decisions (see also Bell 2013). Israel and Hay (2006:2) summarize the outcome:

Social scientists are frustrated and troubled. They believe their work is being constrained and distorted by regulators of ethical practice who do not necessarily understand social science research.

A number of other highly worrisome experiences also came to light in the post-1988 *TCPS* phase. Graduate student Russell Ogden whose promise of confidentiality to research participants in his study of euthanasia was severely (but unsuccessfully) challenged by subpoenas with the compliance of the Simon Fraser University Research Ethics Board (Lowman

and Palys 2000). Paul Grayson (2004; Grayson and Myles 2005) pointed to the absurdity of the legalistic language in letters with consent forms that, in effect, was “killing” survey research. Palys (2005) delved into the problematic nature and limitations of ethics review notions of privacy and confidentiality in numerous research settings (such as child abuse). Heather Kitchin (2003) tackled the narrow interpretations of Canada’s research ethics codes in the matter of using Internet-based data, arguing that most of those data are already in the public domain and therefore the researcher need not receive ethics approval to conduct such research. Khanlou and Peter (2005) demonstrated the shortcomings of ethics policies for participatory action research. Studies of Canadian master’s theses in anthropology (van den Hoonaard and Connolly 2006) and sociology (van den Hoonaard 2006) showed that social science research had, in fact, not declined (contrary to the predictions by many researchers who were critical of the policies), but had changed in the types of topics studied, the collection and analysis of data, and methodology — all to make it more amenable to the demands of research ethics boards (REBs). Significantly, participant observation as a research method declined rather abruptly. Interviews had typically become the *single* and *only* method used by graduate students doing qualitative research. The interview method imitated one of the methods in the biomedical field. Lesley Conn (2008) speaks about ethics policies “exiling” the ethnographic method (see also Tolich and Fitzgerald, 2006). So, within a few years after the appearance of the *TCPS*, its shortcomings became all too apparent to sociologists, anthropologists, linguists, and other social science researchers.

Increasingly, however, Canadian researchers moved their critique from the ethics policies themselves to the functioning and decisions of research ethics boards. Susan Tilley and Louise Gormley (2007), for example, studied how REBs translated principles into practice. Linda Eyre (2007) raised questions about the place of feminist research in the *TCPS*. In the past few years, several ethnographies brought to light the inconsistencies of REB decision-making, each one bearing an evocative title: *Ethical Imperialism* (Schrag 2010), *The Seduction of Ethics* (van den Hoonaard 2011), *Behind Closed Doors* (Stark 2012), and *Academic Python* (Whitney and Schneider, in process). The most recent criticism avers that biomedical research, under the guise of the promulgation of research ethics codes, represents the colonization of the social sciences (and the humanities), as evidenced by a chapter in Kilty et al.’s forthcoming book, *Experiencing Methodology: Narratives in Qualitative Research*.

Thus, researchers have noted the theoretical and pragmatic failings of ethics policies and ethics committees to grasp the essential ethical features of the social sciences, along with an ever-expanding bureaucracy.

These ethical features of social science research are quite different from those articulated in the biomedical model, such as taking field notes, seeing moments of interviews as more than just talking (i.e., taking notes about the surroundings of the interview), preliminary exploration of social settings (where the researcher takes field notes long before the research “officially” starts), aspects of publishing where the social science data can more easily undermine anonymity and confidentiality than is the case in medical research. We also have the case where sociologists interpret their data, calling forth unanticipated ethical dimensions of their research: are they to be critical, skeptical, or analytical of what research participants tell them? What role does friendship with some research participants play in all of this? How do we, as social science researchers, handle hospitality and how does our acceptance of hospitality shape our data and analyses? All of these issues touch ethics, but the usual research ethics codes are silent about them.

These essential features constituted part of conventional social science research, also involving, for example, a heightened awareness of power differences between the researcher and research participants and the value of field research. It is not the unwillingness of sociologists to conduct ethical research, nor even the personal attitudes of members of research ethics boards that stand in the way of an unperturbed journey through “ethics.” The source of the dilemma for sociologists doing ethical research can be found in the structural aspects of the research ethics review process.

CHANGES IN CANADA’S RESEARCH ETHICS REGIME

To offset these shortcomings Canada’s Interagency Panel on Research Ethics (PRE) created, in November 2002, the Social Sciences and Humanities Working Group on Research Ethics (in the hopes of consulting with researchers and academic societies to revise the *TCPS* and to take into account their particular research ethics needs). By 2004, the Panel received 60 statements from the scholarly community (Secretariat on Research Ethics [SRE] 2004). By 2007, the Group received another 94 responses (SRE 2007).² Based on these statements and responses, the Group drafted its key document *Giving Voice to the Spectrum* which became the basis of a chapter on qualitative research in *TCPS 2* (Canadian Institutes for Health Research et al. 2010).

2. Worldwide, many observers have noted the progressive character inherent in the *TCPS*. We believe that the range and number of consultations undertaken by PRE (and by SSHWC) explains this character (see, e.g. Tolich 2013).

While at the policy level the issues moved to eventually create *TCPS 2* to replace the first one, Chapter Ten in *TCPS 2* became a robust chapter on qualitative research. *TCPS 2* recognized the fundamental epistemological issues that underpin qualitative research: it is inductive and iterative, showing that research questions are emergent. Chapter Ten canvassed issues that had been at the heart of Haggerty's ethics creep (2004) and opened the door for researchers to conduct covert research.

Many researchers at the "Ethics Rupture" Summit were looking for a viable alternative to the biomedical model of research. However, Chapter Ten of the *TCPS 2* did not become the subject of much discussion despite the international acclaim it had received; no other international or national codes (e.g., the United States Common Rule, or that of New Zealand) offered as strong a model for qualitative research and social-science research as Chapter Ten (Tolich 2013) and, after all, the chapter could have been the type of alternative the "Ethics Rupture" Summit promised in its promotional materials ("the Summit provides a unique opportunity for scholars to freely exchange ideas about alternative ideas about research-ethics review"). However, it was essential that delegates to this first summit establish the problem (and solution) on their own terms, rather than one "made in Canada." The second "Ethics Rupture" Summit in 2015 will focus more on the alternatives to ethics review as well as restating the eight articles of declaration.

During the October 2012 "Ethics Rupture" Summit to analyze the impoverishment of the social science, especially as a result of the first *TCPS*, it became clear that ethics policies are unlikely to evaporate in the immediate future. It was important to issue a declaration that would, at once, offer a radically new perspective while at the same time acknowledging the continuing existence of ethics policies and their agencies. The "Ethics Rupture" Summit clearly spoke of the need to improve relations between REBs and researchers, but only in a manner that would alter the current fundamental stance in those relations. Delegates considered a novel conundrum that REBs must respect the researcher in the same manner that they expect the researcher to relate to his or her research participant (Article 5 in the Declaration). The Declaration thus strongly declares the vital significance of human relationships in any ethical system, even one that involves reviewing research proposals for their ethical efficacy (Art. 5). Without such an overriding concern about the need to consider ethical relationships between REBs and researchers, one might construe the current approach to research ethics review as an amoral project. For ethics to make sense in the work of ethics committees these committees need to start from the premise that human relationships with researchers should be a central part of the process. The *ethics* review

process itself must incorporate an *ethical* relationship to researchers.³ As an ethical stance, ethics committees can ill afford to “other” research proposals. As soon as that “othering” occurs, there is an ethics rupture that serves no one. It is important not to disconnect the ethics review process from human beings, including researchers themselves.

The participants at the summit also agreed to use the declaration to make other salient points. Chief among these points is the importance and right to conduct research as a vital element for a democratic society that values the freedom of expression (Article 1). No less important, in the declaration, is the need to highlight and present critical and analytical ideas whenever policy makers and others in the research ethics review system talk about past, present, or future ethics codes (Article 7). Understanding the many sides of the ethics review system within the academic setting requires no less than a critical and analytical stance. When viewing social science research, we see that the declaration privileges benefit over risk in research (Article 2). Article 3 highlights the relevance of professional codes in ethics practice. Article 4 speaks indirectly to the problematic nature of ethics when so many parties (ethics committees, academic journals, funders, academic units, etc.) each have their own system of judging the ethicality of research. True to much of what passes as inductive approaches in sociology, the declaration urges experiential teaching and learning of research ethics (Article 6). Finally, Article 8 expresses the wishes of the summit participants to revisit the experiences, insights, and expertise of the researchers to gauge any changes in research ethics regimes.

THE PROSPECTS FOR THE DECLARATION

Unlike other statements borne out of an institutional preoccupation with ethics in research, the declaration is “home-grown” and must rely on its inherent value to be transmitted to those affected by institutional research ethics regimes. In his blog, Zachary Shrag wrote:

It’s only a page long and therefore hardly bears summarizing, but I would note its desire to “encourage regulators and administrators to nurture a regulatory culture that grants researchers the same level of respect that researchers should offer research participants.” That shouldn’t be a radical demand, but it is.⁴

3. Interestingly, the *TCPS 2* requires researchers to follow at least 23 personal virtues, but does not specify any such virtues for members of REBs, although it does assign some virtues to REBs as a body (van den Hoonaard 2013a).

4. <http://www.institutionalreviewblog.com/2013/02/new-brunswick-declaration-seeks-respect.html>

It is gratifying to see that the New Brunswick Declaration has already started to appeal to both researchers and ethics committees in North America, Europe, and the Antipodes.⁵ It has started to appear on websites maintained by ethics committees and of academic societies. During a recent tour by one of the authors throughout Western Canada, it became apparent that one REB wanted to initiate a research ethics review process that underscored relations with researchers as a matter of principle, and is eager to share such an initiative with other REBs. One also hopes that Canada's Interagency Panel on Research Ethics would support such this initiative, preferably in conjunction with a few other REBs, for starters.

The New Brunswick Declaration humanizes the process of research ethics review while not politically undermining the current ethics review structure. In this audit-driven, risk-averse society it is unlikely that this structure will soon collapse and disappear. The declaration is not a compromise, but acknowledges the relevance of human relationships as an integral part of the ethics review process, whether formal or informal.

To further the issues presented in the declaration (see Article 8), there will be a sequel to the "Ethics Rupture" Summit to be held down under at the University of Otago, New Zealand, on 30 January 2015 (<http://www.otago.ac.nz/ethicsreviewproject/contacts/>). The focus of this conference will be balanced between continuing problems with how social scientists navigate through REB review and how social scientists have found alternatives to this problem. For example, what would constitute a good way to educate postgraduate social science students to address the vagaries of REB review and ethics in the field? A second theme explores ethics in practice: how researchers have creatively addressed ethical issues not predicted by them or the REB during the initial ethics review. Third, the summit asks that researchers, including Canadian researchers, provide evidence whether REBs operate from a code of ethics, from their self-generated idioculture, or from a mixture of the two.

5. http://the-sra.org.uk/sra_resources/research-ethics/the-new-brunswick-declaration/; <http://www.sfu.ca/~palys/NewBrunswickDeclaration-Feb2013.pdf>; http://www.google.co.nz/search?sourceid=navclient&ie=UTF-8&rlz=1T4ADFA_enNZ420NZ421&q=new+brunswick+declaration; <http://www.sheffield.ac.uk/education/ethics>; <http://www.institutionalreviewblog.com/2013/02/new-brunswick-declaration-seeks-respect.html>

THE NEW BRUNSWICK DECLARATION: A DECLARATION ON RESEARCH ETHICS, INTEGRITY AND GOVERNANCE RESULTING FROM THE 1ST “ETHICS RUPTURE” SUMMIT, FREDERICTON, NEW BRUNSWICK, CANADA

(Approved 4 February 2013)

The “Ethics Rupture” Summit was a gathering in October 2012 of researchers from Australia, Brazil, Canada, Italy, New Zealand, the United Kingdom, and the United States, who are committed to enhancing ethical research practice, and supporting innovative alternatives to the regulation of research ethics that might achieve this end. As signatories of the New Brunswick Declaration, we:

- seek to promote respect for the right to freedom of expression (**Article 1**);
- affirm that the practice of research should respect persons and collectivities and privilege the possibility of benefit over risk. We champion constructive relationships among research participants, researchers, funders, publishers, research institutions, research ethics regulators, and the wider community that aim to develop better understandings of ethical principles and practices (**Article 2**);
- believe researchers must be held to professional standards of competence, integrity and trust, which include expectations that they will act reflexively and responsibly when new ethical challenges arise before, during, and long after the completion of research projects. Standards should be based on professional codes of ethical practice relevant to the research, drawn from the full diversity of professional associations to which those who study human experience belong, which include the arts and humanities, behavioural, health and social sciences (**Article 3**);
- encourage a variety of means of furthering ethical conduct involving a broad range of parties such as participant communities, academic journals, professional associations, state and non-state funding agencies, academic departments and institutions, national regulators and oversight ethics committees (**Article 4**);
- encourage regulators and administrators to nurture a regulatory culture that grants researchers the same level of respect that researchers should offer research participants (**Article 5**);
- seek to promote the social reproduction of ethical communities of practice. Effective ethics education works in socially embedded settings and from the ground-up: it depends on strong mentoring, experiential learning and nurturance when engaging students and novice researchers with ethics in research settings (**Article 6**);

- are committed to ongoing critical analysis of new and revised ethics regulations and regimes by: highlighting exemplary and innovative research ethics review processes; identifying tensions and contradictions among various elements of research ethics governance; and seeing that every venue devoted to discussing proposed ethics guidelines includes critical analysis and research about research ethics governance (**Article 7**), and
- shall work together to bring new experience, insights, and expertise to bear on these principles, goals, and mechanisms (**Article 8**).

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