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Measuring the Impact of the New Brunswick Declaration

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Abstract

The purpose of the article is to measure the impact of the New Brunswick Declaration.

The results of the study are in three parts: The first part of this article backgrounds the calling for the Ethics Rupture held at the University of New Brunswick in 2012 that produced the New Brunswick Declaration. The body of the article then measures the impact the New Brunswick Declaration has had on the international social science research community in terms of scholarly writing. The article concludes by reaffirming the Declaration as a living document: Its revision will occur at an ethics conference to be held in New Zealand in 2015.

The methods are a google search of any mention of the Declaration.

Key words: New Brunswick Declaration; Scholarly writing; Ethics rupture

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INTRODUCTION

Uncertainty and doubts mark the sojourn of Canadian sociology within the unpredictable waters of research-ethics review during the past fifteen years (van den Hoonaard 2014). It is not, however, due to the unwillingness of sociologists to conduct ethical research, nor even the authentic sincerity that typically characterizes many members of research ethics boards (REBs). The fundamental approach of ethics review processes derived from biomedical histories and discourse is, at present, ill suited to address sociology research.

Admittedly, Canadian Sociologists are better placed than their USA colleagues whose research existence is questioned by the continued adherence to the Belmont Report's definition of research as something that "contributes to generalizable knowledge" (Belmont Report, 1979, p.3). Canada's *Tri-Council Policy Statement on Research Involving Humans Subjects* (Medical Research Council et al., 1998), revised as TCPS 2 in 2010, is more user friendly to Sociology in defining research as an "undertaking intended to extend knowledge through a disciplined inquiry or systematic investigation" (TCPS 2 Chapter 1). However, the authors of TCPS 2 restrict their discourse to research policies themselves, leaving the implementation of policies to locally organized REBs, and there is little evidence to suggest that REBs employ the TCPS 2 code to make approval decisions. If REBs are like USA committees, they make many decisions, instead, along idiosyncratic lines and based on committee precedent (Stark, 2012).

Systems of research ethics governance in many other countries depend on a national set of rules or guidelines and local review committees, and they depend on their associated bureaucracies to interpret them and police their application (Israel, 2012). These forms of regulation, however, are not uniform. Dingwall (2012, p. 4) reports:

> *There are though, still parts of the world, particularly mainland Europe that retain and cherish traditions of professional autonomy, offering an alternative to the Anglo-Saxon movement towards a system of command and control. What did Anglo-Saxon social scientists do that was so catastrophically wicked that it justifies this change? Has it produced identifiable social benefits or are these outweighed by the direct and indirect costs?*

THE ETHICS RUPTURE

Qualitative research and its emergent or iterative research designs prove most problematic for REBs for a number of well documented practical and philosophical reasons. For example, Fitzgerald (2006) posed a question for REBs: What form would ethics oversight take if organised by ethnographers. She suggested REBs ask researchers four questions: a) what is the research about, b) what are the ethical issues, c) how will the researcher address these issues. These three questions are standard REB questions. However, Fitzgerald asked a fourth question that captures the emergent and iterative nature of ethnography. Question 4 asks the researcher, what do they plan to do when they get into the field and their informant lead methodology changes both the research question and the ethical considerations that underpin it.

Two facts emerge from this fourth question. Sociologist must devote more time to preparing their postgraduate students for the field when many ethical problems "have to be resolved *situationally* and even spontaneously" (Punch, 1994, p.84). The second fact is that as long as REBs adopt a positivist model, assuming research is linear and deductive as embodied in most bio-medical research, REB decision-making will remain irrelevant to sociology (Israel & Hay, 2006). Yet the influence of the positivist biomedical approach is multi-layered. At one level, sociologists are quick to point to some of the most obvious discrepancies between bio-medical research and sociology in particular, and the social sciences in general (van den Hoonaard and Tolich 2014): ethics regimes artificially construct the starting and closing dates of research leaving no room for covert research, ethics regimes offer nothing in the way of ethical guidance when it comes to writing and publishing research, regime terminologies are foreign to the ears of social researchers (e.g., "protocol," "investigator"), the tone of the ethics codes discourages questions about challenging the status quo (which is the sociologist's staple of research), and ethics ideology confines the idea of "justice" to notions of methodology, making sure that all have an equal chance of being selected to participate in the research (rather than relating the concept to social justice), and so on. At a deeper level, there are vastly more influential aspects of the bio-medically driven research-ethics regime that sunders and confounds the sociological imagination and approach.

The need for "informed consent" is something that every REB cries when scrutinizing applications from researchers. There is, however, a very fundamental reason why the idea of informed consent is so preciously guarded in research-ethics codes. In the context of medically-driven research, the medical researcher is accustomed to having enormous power that can easily override the interests of the "subject." Routinely clinical trial consent forms are twenty five pages of legal jargon that best suits the sponsor's fear of litigation more than providing information to a research volunteer that is comprehensible. In sociological research, however, the exercise of such power is fairly uncommon and the consent forms readable. In study after study, sociologists typically assign a lot more power to research participants than to themselves. What constrains the sociologist is the pre-existing respect he or she already has the research participant. Thus, the idea of "free and informed consent" occupies a different space in social research.

Furthermore, policymakers derive a notion of *individual* harm, and the need to prevent it, from the work of bio-medical researchers. No one argues that harm should come to individuals, however, the sociological project involves the public interest, not necessarily the interest of individuals. As Matt Sleat (2013) observes:

> While the harm social science research might do can clearly affect the individual and many of their private interests, it is their public role that is of interest to us (though admittedly these are not easily separable). The point is that social science research only harms the private interests of individuals indirectly, as an often inescapable ramification of pursuing their public responsibility to study and analyse public matters.

Lastly, informed consent is, at present, a narrow one off manifestation. As stated above, the iterative nature of social science requires most robust consent processes, such as the notion of process consent (Ellis, 2007) that reconsents participants at the beginning and the end.

Becoming more apparent are the major philosophical underpinnings that form the basis of significant disruptions that are rapidly becoming common place in the way sociologists are constraining their work. For example, research governance (Iphofen, 2009) has so enveloped the research-ethics review process that rigidity, conservatism, risk-avoidance, and safeguarding against liability are the substance of approval decisions. The outcome is summarised by Israel and Hay (2006, p.1): "Social scientists are angry and frustrated, their work is constrained and distorted by restrains of ethical practice who do not necessarily understand social science research."

The TCPS 2, especially its chapter on Qualitative Research is undoubtedly a step forward over the biomedically driven TCPS 1 that Van den Hoonaard (2001) labeled a 'moral panic' and Haggerty (2004) calls an 'ethics creep'. But how does this step forward move towards a change within REBs decision making processes? The past few decades have seen no satisfactory attempts on behalf of biomedically driven REB policymakers to craft policies that are responsive to social research, yet REBs continue to struggle fitting a round peg into a small square hole (Fitzgerald, 2006). Researchers themselves voice a growing impoverishment of their research,homogenization of their discipline, and a withering away of respect for (social scientists as) persons.

Since 2000, almost 200 scholarly publications including books (Schrag, 2010; van den Hoonaard, 2011;

Stark, 2012), book chapters, and articles worldwide have recorded the troubled histories of scholars with ethics regimes and ethics committees. In addition, there are voiced experiences of these troubles that have garneered considerable attention across the board of all ethics committees. Moreover, annual gatherings devoted to discussing research-ethics policies and practices, have raised these issues. The academic world is also witnessing the appearance of historical and ethnographic work that, without reserve, point to the dilemmas that ethics policies create for sociologists and other social scientists.

Will van den Hoonaard's *The Seduction of Ethics* (2011) provides an evidence- based account of ethics review and the problems it creates for social science research. The book consists of 15 chapters, thematically grouped into three parts: (a) archeology of ethics review, (b) ethics review process, and (c) researchers vis a vis formalized and externalized ethics (Gontcharov, 2011).

Perhaps most importantly, van den Hoonaard's work shifts the focus from identifying and substantiating concerns for social science research to generate effective strategies to 'decolonize' social scholarship and establish alternatives to ethics review. To that end, in an effort to explore the conceptual and regulatory alternatives to prospective ethics review, van den Hoonaard sought funding from the Social Sciences and Humanities Research Council of Canada, with also some funding from St. Thomas University and the University of New Brunswick (both in Fredericton, New Brunswick) to convene the 2012 'Ethics Rupture: An Invitation Summit about Alternatives to Research-Ethics Review.'

2. THE ETHICS RUPTURE SUMMIT

It was in this climate of the great chill that a number of researchers at the University of New Brunswick and St. Thomas University felt emboldened to organize the "Ethics Rupture Summit" in Fredericton, Canada, 25-28 October 2012. With over 30 scholars in attendance from Australia, Brazil, Canada, Italy, New Zealand, the United Kingdom and United States, the Summit outlined the broad collection of problems with the research-ethics process that are now quite widespread. Summit discussions and presentations are podcasted at: http://wp.stu.ca/ethicsrupture.

The participants agreed to a Declaration (The New Brunswick Declaration on Ethics in Research and Governance) which makes several points salient. Chief among these points is the right to conduct research as a vital part of a democratic society that values the freedom of expression.

The full text of the 328 word New Brunswick Declaration claims to:

> a) Seek to promote respect for the right to freedom and expression;
>
> b) 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;
>
> c) 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, behavioral, health and social sciences;
>
> d) 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;
>
> e) Encourage regulators and administrators to nurture a regulatory culture that grants researchers the same level of respect that researchers should offer research participants;
>
> f) 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;
>
> g) 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, and;
>
> h) Shall work together to bring new experience, insights and expertise to bear on these principles, goals, and mechanisms.

Taking their cue from *The Seduction of Ethics*, participants focused primarily on the impact of ethics regimes, relations between REBs and researchers, and the role of knowledge in risk regulation. Participant Ron Iphofen summed up the rupture as "not just a conference of whingeing, if valid, complaints – it sought a way of moving beyond the rigidities of formalized ethical review" (Iphofen, 2013).

Since February 4, 2013, the Declaration has experienced considerable and varied application within research programmes. The United Kingdom Social Research Association has adopted the Declaration as part of its ethical guidelines for social researchers, and so too has the University of Sheffield's School of Education (Mauthner, 2013). The declaration is also placed on The Humanities and Social Sciences Network (H-Net) website, and the Science Codex directory. Prominent Canadian sociologist and longtime critic of Research Ethics Boards Ted Palys have also placed the Declaration on his website. Fluehr-Lobban (2013) also makes use of the declaration in her textbook *Ethics and Anthropology.*

A number of scholars have written to praise the Declaration for its timely, simple, yet potentially profound influence on social science research. Mark Israel (2014) one of the co-drafters of the Declaration saw the document as a milestone:

> The Declaration was intended to support a constructive dialogue between various groups with an interest in nurturing ethical research and complementary regulatory practices. In particular, we hoped it might offer some international support to researchers seeking to influence future regulatory practices in their own institutions and jurisdictions.
>
> The Declaration was designed to reflect the concerns of signatories without over-generalizing from the negative experiences of a particular jurisdiction or institution at a specific time. While constructed to be aspirational, the Declaration sought to avoid excessively burdensome commitments that might be difficult to sustain.

Gontcharov (2012) who took part in the Summitt summarizes the importance and impact:

> New Brunswick Declaration envisions an alternative approach to research governance based on ethical and methodological pluralism, which would encourage research initiative while promoting the interests of research participants. New Brunswick Declaration engages critically with the biomedical monopoly on articulating the principles of ethical governance, the problems with ethics review process, and the erosion of intrinsic ethics- the process that accompanies the externalization of research ethics and the establishment of the formal system of ethics review. The Declaration proposes a multilateral approach, and highlights the role of professional associations and valid research standards. It shifts the focus from individuals exclusively to individuals and collectivities. It emphasizes the necessity of promoting existing ethical communities of practice and of supporting socially embedded contextual ethics education. Importantly, it calls for continued critical examination of the system of ethics review, and collaborative elaboration of the alternative to the current regulator culture… The New Brunswick Declaration offers a way out of the impasse, by embracing an ethical pluralist platform as a possibility for restarting the conversation on the principles of ethical governance in academic research.

van den Hoonaard and Tolich (2014) describing the nuance of the Declaration as a constructive critique in the Canadian Journal of Sociology:

> 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 adverse 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.

In their preface to the twenty-two chapter volume on The Ethics Rupture Van den Hoonaard and Hamilton (2014) also claimed the positive nature of the Ethics Rupture:

> [The Declaration] sets out new type of concepts and relationship among ethics committee members, researchers, an others involved in research- a relationship that reduces the wholesale negative, unhelpful, imposing manners of ethics committees.

Shrag (2013) in his Institutional Review Blog frames the Declaration's Article 5 which *Encourage[s] regulators and administrators to nurture a regulatory culture that grants* researchers the same level of respect that researchers should offer research participants by blogging:

> 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.

Van den Hoonaard (2013b) in the Journal of Empirical Research on Human Research Ethics also comments on Article 5 by stating:

> This principle is stunning in its simplicity and in its potential for reforming the ethics review system. Currently, committees charged with making researchers compliant with ethics codes control their interactions with researchers. These interactions can be quite unsatisfactory; the bureaucratic setting makes it very difficult to treat researchers as collaborators. We aver that ethics always involves human relationships. If a system disregards the elemental fact of the process, it will sow the seeds of discord and enmity, as is evidenced now.

The New Brunswick Declaration appears uniquely able to penetrate the decision-making process of REBs. Van den Hoonaard (2013b) reports Research Ethics Boards in Canada, England, New Zealand, Australia, and the US are becoming increasingly aware of the Declaration. As evidence of this Van den Hoonaard and Tolich (2014) note:

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 relationship with researchers as a matter of principle, and is eager to share such an initiative with other REBs.

International conferences have demonstrated persistent interest in the Declaration and emerging themes of the Ethics Rupture Summit. During the Australasian Ethics Network (2013), Professor Mark Israel presented "Research Ethics Governance: Plotting the Demise of the Adversarial Culture" which discussed the increasing adversarial culture in Australia between researchers and regulators, and the emergence of better informed process of review and the drafting of the New Brunswick Declaration. Professor Israel had earlier presented this speech at a public lecture hosted by the Auckland University of Technology in August 2013.

CONCLUSION

Collectively, these positive regards and popular discussions indicate a wide acceptance of the New Brunswick Declaration. The Declaration presents itself an opportunity to begin changing the ethics review decision-making processes by shifting fundamental perspectives on researcher/regulator relationships and reclaiming space within ethics-related discourse. In doing so, the Declaration contributes to new circumstances from which sociology research may find satisfaction and begin to recover from its experienced restraint and position of impasse.

Moreover, the New Brunswick Declaration is a living document that requires critique for its continual revitalization and relevance. One of the authors is organizing an ethics conference in 2015 to be held in New Zealand. The conference theme is "ethics in practice" and a major sub-theme of the conference will be the "Ethics Rupture". There will be a call for papers to further relevant discussions; Professor Will van den Hoonaard will be a key note speaker; the final day of the conference will redraft the second version of the New Brunswick Declaration. Additionally, the conference will also serve as the book launch of Van den Hoonaard and Hamilton edited collection of chapters documenting the first Ethics Rupture.

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