

The New Brunswick Declaration on Research Ethics, Integrity, and Governance

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Received date: February 09, 2016; Accepted date: March 30, 2016; Published date: Mar 31, 2016

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Keywords: Research ethics; Brunswick declaration; Integrity; Governance

Introduction

Despite their growth and extension of power, overworked ethics review committees are limping along. Many have commented on the structural problems of the regime: the inability of ethics committees to make consistent decisions [1,2] the inability of ethics committees, despite their local strength, to effect any necessary policy changes, and the long periods of abeyance for national agencies to bring about essential amendments in ethics codes. Other scholars (some are listed in endnote 2) have found other weaknesses in the system. Finally, The costs are astronomical [3,4].

This paper explores the need for research ethics-review committees to nurture and maintain ethical relations with researchers¹. First, the paper explores the unbalanced spread of ethical obligations imposed by Canada's TCPS 2 [5] on individual REB members and on researchers, respectively. This imbalance shows that ethical relations with researchers are not the primary consideration in TCPS 2: ethical imperatives for individual REB members and for researchers are so divergent that it is difficult to build ethical relationships between the two stakeholders. It then discusses the New Brunswick Declaration on Research Ethics, Integrity, and Governance resulting from the 1st Ethics Rupture Summit, held in October 2012 in Fredericton, New Brunswick, Canada. The Declaration is one of the most recent formal expressions of the need for such ethical relations.

The disquiet around research ethics codes is having a profound effect on the conduct of research, especially on the social sciences. Since before 2000, an estimated 335-350 articles have appeared in the social science literature that describe in agonizing detail how research ethics codes are missing the mark as far as the social sciences are concerned². Numerous are also the key journals that include articles which point to this pervasive dislocation of the social sciences³. We also witness the publication of books and the holding of conferences

that underscore the problematic nature of the ethics regime for social scientists. Some propose the full abandonment of these codes, partly because many academic societies already have well-established ethics practices; others offer piecemeal solutions.

Many researchers in the social sciences have fully surrendered themselves to the inevitability of needing to comply with formal ethics codes. They are even using the language and terminologies more common in the bio-medical and clinical trial fields rather than those used in the social sciences themselves. Some argue that this trend portends a form of colonization by the medical sciences at the expense of the culture of the social sciences [6,7].

One cannot but help notice the relentless process of students to narrowing their research sights to the strictures of ethics codes in a manner that is both frustrating and often quite unhelpful to students. However, it is ironic that with their emphasis on protecting people in vulnerable contexts, ethics committees (IRBs in the USA, and REBs in Canada) overlook the fact that students are de facto a vulnerable population.

Uneven Disbursement of Ethical Obligations

Many problems with the ethics regime stem from the fact that ethics committees do not see themselves as ethical agents. Rather, they see themselves as enforcers who are keen to compel researchers to follow rule-bound decisions of committees-hardly a condition for an ethical relationship [8-13]. Moreover, ethics codes demand more from researchers insofar as personal virtues are concerned. Canada's research ethics policy, TCPS 2, contains thirteen chapters. My analysis of the spread of personal virtues only takes into account TCPS 2's general chapters (i.e., 1 to 8) because those chapters affect all researchers and REB members, regardless of discipline or topic. The chapters contain 136 mandatory provisions for all parties who have a stake in implementing TCPS 2 (2014). TCPS 2 contains 514 'should's. Of the 136 ethical provisions⁴, TCPS 2 spells out no fewer than 88 ethical provisions for researchers (or, almost 2/3 of the total). At the

¹ More typically, it is the social science journals that carry articles related to the disgruntlements of social scientists with ethics regime. It is important for journals like the Journal of Clinical Research & Bioethics to carry an article such as this one.

² My own personal bibliography on ethics in social science research lists 330-350 articles. Medical researchers have also underscored the problematic nature of ethics regimes. See Whitney (2012), Edwards et al. (2004), Fistein and Quilligan (2012), Fost and Levine (2007), Garrard and Dawson (2005), Goldacre (2008), Jamrozik and Kolybaba (1999), van den Hoonard (2002, 2006), Wynn (2016), and Minnis (2004). Upon request I will make this bibliography available to anyone so interested.

³ American Ethnologist, Anthropology News, American Psychologist, Canadian Social Work Review, Chronicle of Higher Education, Educational Researcher, IRB: Ethics & Human Research, Journal of Applied Communication Research, Journal of Empirical Research on Human Research Ethics, Qualitative Inquiry, Qualitative Research, Qualitative Sociology, Signs: Journal of Women in Culture and Society, Sociology, and so on.

⁴ The TCPS 2 (2014) explains that mandatory provisions are signaled by the use of the term "shall" whereas guidance for the interpretation of the core principles is generally indicated by use of the term "should." The whole TCPS 2 contains 298 'shall's, 514 'should's, and 121 'must's. Some of these provisions are cast as "research directives."

other extreme-and what is no less intriguing is the fact that individual members of ethics committees are bound by only two ethical provisions which appear in the chapter on Conflicts of Interest. Such a divergent weight of ethical principles is bound to produce strains and ruptures in the system. This imbalance of virtues (i.e. what is expected of individual committee members and of individual researchers) and the paucity of ethical obligations imposed on REB members drive home even further the dissatisfaction researchers feel towards REBs in general.

Who, indeed, is inclined to follow ethical provisions which are relatively absent from the mandated conduct of ethics committee members, but fully set out for researchers? The United States codes (45 CFR 46) is no different⁵. It spells out at least 22 ethical imperatives for researchers (a number of them are dressed up as research directives); only one is directed at individual members of IRBs (§46.107) and that one pertains to conflicting interests. The presentation of qualifications of these members (§46.103.3) makes no mention of any virtues or ethical principles that each should be noted for, such as fair dealings with researchers and students, and valuing methodological diversity. We now turn our attention to The New Brunswick Declaration on Ethics in Research which was created out of a deep concern about this imbalance.

The New Brunswick Declaration on Ethics in Research

Over 30 scholars from around the world convened in Fredericton, Canada, 25-28 October 2012, to collectively consider the diminishment of the social sciences as a result of the growing number of ethics codes and regimes proliferating around the world. Known as the “Ethics Rupture Summit,” (Supplementary 1) this gathering explored new ways of understanding and addressing the fundamental problems of ethics regimes⁶. Its end-document, the New Brunswick Declaration (see Appendix A), not only expressed the well-considered sentiments of these researchers, but also set out a simple, but radical solution: members of ethics committees should treat researchers in the same way that they expect researchers to treat research participants.

Until recently, the main force of complaints by social scientists was the use of the bio-medical paradigm to articulate research-ethics codes. This paradigm has been found wanting, seriously so. Increasingly, what captures the essence of ethics regimes is the need to see them as enterprises of control and enforcement. In that connection, the New Brunswick Declaration highlights the need to view relations between ethics committees and researchers as ethical⁷. In matters of research-ethics governance, is it not logical that those relations with researchers be ethical?

The New Brunswick Declaration highlights a number of significant points. The Declaration explicitly connects to the Universal Declaration of Human Rights and extends ethical principles beyond the regulatory culture of ethics regimes in particular, the right to freedom of expression, the right to conduct research, and the right of researchers to be respected, not demonized⁸. Robert and Dingwall [3]

see a tight connection among these rights, but social scientists pay an entry price “with the spread of pre-emptive regulation:”

The ecology of societal audit is being disrupted in ways that may not be beneficial. As ethics regulation directs [social science] research away from ‘difficult’ populations, topics, and methods, it creates systematic areas of ignorance about social conditions. Without such knowledge, however, it is difficult to create the transparency among people that promotes better lives [3].

Creative artists and journalists, who [3] see as “central pillars of democratic societies,” pay “a much lower social cost to express themselves,” lacking any “pre-emptive regulation.”

What stands out in the Declaration is the value placed on the relevance of collectivities and communities which the term “persons” as individuals does not sufficiently convey. Society is not an aggregate of individuals. As I claim [14], society constitutes “a pattern of social action, [and] a culture that requires its own approach and method of analysis.” The implications are more far-reaching than one realizes at first. Is it, for example, futile to seek individual informed consent? Researchers can learn from the practices of aboriginal researchers on how community consent is actualized.

The idea of privileging benefit over risk strikes at the root of many taken-for-granted assumptions about ethics in research. The uncertainties and risks associated with medical research take on a different hue in social research where one does not find the same intense risk as in medical research. The idea of privileging benefit over risk in research “communicates the importance of not having research stray too far from its essential purpose: to bring benefits” [14].

The Declaration believes that professional codes of ethical practice are highly relevant. One needs to move away “from beneath the shadow of a bureaucracy” [14] and the obsession to maintain “compliance.” Research ethics practices will thusly gain a new life, beyond the usual culprits: checklists and standardization across a broad spectrum of research [15]. A true scholar acknowledges diversity and flexibility of ethical practices (Figure 1).

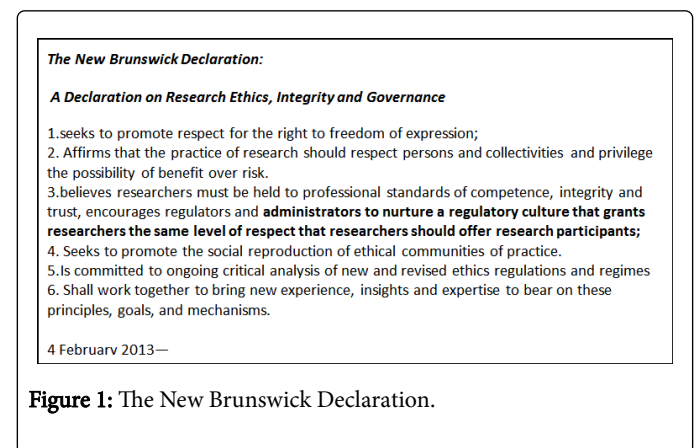


Figure 1: The New Brunswick Declaration.

⁵ <http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html>

⁶ A new book, The Ethics Rupture: Exploring Alternatives to Formal Research Ethics Review (van den Hoonard and Hamilton, 2016), contains the presentations made at that Summit.

⁷ Some of the publications that have described the New Brunswick Declaration in greater detail include van den Hoonard (2013a, 2013b, and 2014a)

⁸ I still regularly hear claims by REB members that researchers are “lackadaisical,” “slovenly,” or “lazy” when it comes to conducting ethical research.

There are not many scholarly-publishing venues left that do not require a formal acknowledgement that the research has “passed ethics.” Such a mention has become a trite exercise and reveals not much about the intricacies of doing ethical research. I call this system of up- and down linkages of ethics approval as “vertical ethics” [16-20]. The system of vertical ethics can produce less than desirable results. The home IRB might approve the ethics of the research, but a journal might still foreclose on the publication of an article, using an ethics temperature gauge that is at odds with the original basis of approval. The Declaration argues that vertical ethics holds many problems without making the research (or the publication of such research) more ethical.

The Declaration introduced a principle that is stunning in its simplicity: why shouldn't ethics committees afford researchers the same respect as ethics committees expect researchers to treat research participants? The Declaration argues that the conventional, adversarial relations between ethics committees and researchers should be transmuted into an ethically more viable relationship [21-24].

There is a longing, whether inside the formal ethics regime or outside of it, that students as upcoming scholars get a taste of what ethical research is like. It is hard to know how ethics in research can be taught. When ethics staff is invited to teach about ethics, the most predominant approach is about how to prepare ethics applications and forms—hardly a matter of teaching students how to reflect on ethics in research [25-27]. The CITI (Collaborative Institutional Training Initiative) comes to mind, but there are enough criticisms of this ethics-testing method that suggest it is relatively meaningless [17,18]. Students (and faculty) have found ways to circumvent the test either by using split or alternate screens on their computer. It appears though that the one thing that CITI inadvertently teaches is cynicism. There are too few questions in the CITI that actually show what research is like in the social sciences [28]. There is no replacement for “strong mentoring, experiential learning, and nurturance” to “engage students and novice researchers with ethics in research settings” [14].

Social scientists, by outlook, training, and practice, are accustomed to challenge taken-for-granted issues, both in their teaching and research. Plenty are university courses that deal with racism, urban blight, gender, intellectual history, using the critical eye. No area of human endeavour is exempt from thoughtful and critical analyses. The one obvious exception is ethics-policies conferences where one very seldom hears such analyses. There is much to be gained from hearing contrary points of view. A course critical of the university's ethics committees would, in the end, create an understanding and acceptance of ethics policies. Off campus, social scientists feel a high sense of discomfort when such conferences are really faits accomplis engineered by agencies that intend to promote acceptance of new policies. Bubble wrapped, these gatherings offer no means of placing ethics policies under a microscope [29]. The Declaration urges the incorporation of critical and scholarly analysis as a significant feature of such gatherings. At the same time, the Declaration promulgates the idea that every gathering should not only include the importance of “highlighting exemplary and innovative research ethics review processes; [but also] identifying tensions and contradictions among various elements of research ethics governance.”

Without any formal institutions promoting the New Brunswick Declaration, it is anyone's speculation how far the Declaration will resonate within the ethics sectors. It represents a move away from the bureaucratic structure of the current ethics regimes, and posits an ethical relationship between ethics committees and researchers [30,31].

The current ethics regimes may have already travelled too far and invested too much energy and resources to effect an ethical turnaround in how business is conducted. The hope for change relies heavily on the notion that social change is often abrupt, witness the Berlin Wall's suddenly collapsing. That collapse was unheralded. When we turn our vision skyward, we see flocks of birds changing their flight course at a moment's notice. Can we speculate that changes in the research ethics codes can be as sudden? A future paper may well discuss the influence that ethical relationships between REBs and researchers will have on research.

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