Alternative Models of Ethical Governance:
The 2016 New Brunswick-Otago Declaration on Research Ethics

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ABSTRACT

The current model of ethical governance in research involving humans in the social sciences and humanities relies on prospective ethics review in ensuring that research in conducted ethically. One of its key features is distrust to researchers and their initiatives regardless of the subject matter, discipline, research methodology or settings, sources of funding, or researcher's experience. This paper discusses the *New Brunswick Declaration on Research Ethics* adopted by the participants of the *Ethics Rupture: Alternatives to Research-Ethics Review* Summit in 2013. In particular, it provides background for the regulatory capture of the social sciences by the biomedical institutions of ethics review. It concludes by examining the limitations of the Declaration, and offers a set of principles for the development of the New Brunswick Declaration following its discussion at the *Ethics in Practice: Tensions around Ethics Review and Maori* Consultation Conference at the University of Otago in Dunedin in May 2015.

The 'Ethics Rupture: An Invitational Summit about Alternatives to Research-Ethics Review' took place in October 25-28, 2012 in Fredericton, New Brunswick, Canada. The Rupture produced the of a *Declaration on Research Ethics, Integrity and Governance (*W. C. van den Hoonaard 2013). If previously there were only fragmentary voices of criticism and discontent with the expanding system of ethics review, then with the adoption of the New Brunswick Declaration there emerged a clear point of reference, a policy reform platform.

The New Brunswick Declaration is an important element in the governance of research involving humans – directly as a grassroots initiative, a code of ethics, or even a counter-code, designed by social researchers themselves; and symbolically – as a representation of a network of social researchers who seek to address the tensions between the institution of ethics review and ethical challenges that social researchers face in their day-to-day practice, by (a) articulating relevant to their disciplines – 'indigenous' approaches to research ethics, and (b) documenting the limitations of regulatory transplants from the biomedical field.

The value of the New Brunswick Declaration is also as a barometer of the changes in the ethics governance in various jurisdictions. This paper provides a Canadian and New Zealand context to the elaboration of the New Brunswick Declaration. In Canada the focus is on the on-going development and implementation of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS) in 1998.* In 2010 the second edition was adopted (TCPS 2), and updated again in December 2014 (TCPS 2 2014).

New Zealand research ethics governance has been less regulated in social science and overall has had a more stable regulatory environment than Canada in the last 10 years. For instance, New Zealand has no overarching regulatory regime for prospective and ongoing ethics review of research in humans, except in the Health and Disability sector. The Health and Disability committees (HDECs) are creatures of the Minister of Health who appoints the committee members, sets their operating procedure and ambit. Any other human subject research is reviewed only if the researcher's institution (e.g. university) has a review board. However, the autonomy of the most social science research in New Zealand ethics review does not mean that research in humans in New Zealand is closer to the aspirations of the New Brunswick Declaration. Recent research by Tolich and Smith (2015) has confirmed that the current New Zealand ethics regime is adapting global biomedical norms inhibiting social science research, and the quality of the ethics review of health research has been severely curtailed by political interference (Tolich and Smith, 2015). At the same time, New Zealand researchers note that they can learn from and build upon the centralized approaches, such as TCPS, especially in regard of the governance of indigenous research (Tolich and Smith, 2015).

The latest opportunity for international scholars to consider the New Brunswick Declaration in the context of global challenges in the governance of research in humans occurred at the *Ethics in Practice: Tensions around Ethics Review and Maori Consultation* Conference at the University of Otago in Dunedin in May 2015. Several panel discussions, seminars and a keynote were held focussed on the New Brunswick Declaration, with talks by many of the original scholars who contributed to the New Brunswick Declaration

Codification of Ethics

The 'signing' of the New Brunswick Declaration took place in early 2013 –fifteen years after the 'harmonized' policy extended the institution of ethics review to all research involving humans in Canada, and close to twenty years after a similar initiative was considered in New Zealand, following the Cartwright Inquiry (Tolich & Smith, 2015). During 1990s codes of ethics were emerging in every field as part of the global ethics movement. In general, the creation of the codes of ethical conduct was a copy/paste activity reflecting an expectation to produce a code of ethics, but occasionally they were based on the existing unwritten set of ethical rules. For the most part these codes are soft law, general guidelines, and collections of best practices. However, in academia the codification of ethical principles resulted in a system of licensing (Hamburger, 2007) based on the prospective ethics review of individual research projects by multi-expert panels. The adoption of prospective ethics review as a central element of research governance introduced a totally different governance model – a model based on distrust to researchers, which was also introduced in a paternalistic manner – without a public discussion and necessary justification of its basic principles, relevance and effectiveness in the social sciences and humanities.

This model has effectively disempowered researchers individually and as a social group, undermining their ability to self-governance via professional associations, and professional socialization through existing academic institutions. It has put under

question the ethico-methodological expertise and professional integrity of academic researchers. Meanwhile, it has given rise to a new profession, members of which are known as Research Ethics Board (REB) professionals or experts in the procedural aspects of ethics review. Thus The Canadian Association of Researcher Ethics Boards (CAREB) Professional Development Committee is currently "working on an initiative to develop a Canadian certification program for REB professionals, based on Canadian policy and legislation". Since the task of REB professionals is to interpret and apply the Policy, which continues to be poorly adapted to the ethical landscape of the social sciences, tensions started to emerge between ethics committees and researchers. *Article 5* of the New Brunswick Declaration, "[we] encourage regulators and administrators to nurture a regulatory culture that grants researchers the same level of respect that researchers should offer research participants", emphasizes the existing imbalances of power and proposes that the culture of mutual respect should be a feature of research governance in general, including relationships between researchers on the one hand and REBs and the Interdisciplinary Advisory Panel on Research Ethics on the other.

The system of prospective ethics review emerged as an attempt to manage the social trauma of being used as 'guinea pigs' in the government-sponsored biomedical research. In this sense the institution of ethics review is a reflection of a 'moral panic' (W. van den Hoonaard, 2001 & Tolich, 2001). Meanwhile this event can be also understood as a moment of self-reflexivity on the side of the government, which realized that federally funded research has not always been conducted in accordance with the 'highest' ethical standards. However, instead of introducing additional scrutiny for government-sponsored research – an effective model of public oversight over governmental research initiatives, it established a quickly expanding institution that currently covers all research involving humans regardless of the source of funding, research discipline and methodology. Although there were several reasons triggering the expansion of the new institution, it is important to notice that the language of 'highest standards' was and remains problematic for Canada, since TCPS 1 was, in fact, introducing minimally-acceptable standards, yet giving the power to Research Ethics Boards to raise them 'higher' thus promoting risk-aversive and speculative approach by reviewing social research prospectively. The outcome was a bureaucratic expansion of ethics oversights, Haggerty (2004) labels ethics creep.

In 2010 TCPS doubled in size from the first edition, and became part of the 2011 *Tri-Agency Framework: Responsible Conduct of Research* Furthermore, the Interagency Advisory Panel on Research Ethics opened a rapidly expanding *TCPS 2 Interpretations* section on its website in 2010. Some of the interpretations are unavoidably candidates for subsequent codification and thus further expansion of the normative framework.

In New Zealand, a 2012 review of the standard operating procedures of the ethics committees in the Health and Disability sector empowered a secretariat based in the Ministry of Health to act as a clearing house for all applications to HDECs, including the power to decide which applications needed HDEC approval, and which did not. In the University sector, the health research regulations and funding streams created an impetus to adopt the Health Research Council standards of ethics review. Thus, like in Canada, normative standards were rapidly promulgated amongst all New Zealand ethics committees, undermining the original attempt to devolve ethics

decisions to local institutions and communities leading a specialization in ethics review.

Specialization

In Canada, although specialized ethics boards were not envisioned in TCPS 1, the need for particular expert knowledge in ethics review was recognized through such requirements as presence of community members, experts in relevant research methodologies and health law. Furthermore, after the adoption of TCPS 1, it became obvious that a decentralized model of research ethics governance and the institutional character of ethics review is an obstacle to multicentre clinical trials. The need to obtain approval at all research sites not only delays the onset of research and increases its costs, but also creates additional ethical challenges for researchers due to an idiosyncratic character of REBs' decision-making, resulting in differences in the assessment of research projects. Local circumstances, including differences in available ethico-methodological expertise, in knowledge, interpretation and application of regulations, in understanding of risk and risk management, in addition to a number of psychosocial factors influencing group dynamics, influence how REBs consider proposed research projects.

Consequently, a number of initiatives emerged to address this situation, which can be understood in terms of increasing specialization of ethics committees, but they are also part of the processes of centralization. Clinical Trials Ontario is one of the examples of an agency, the task of which is to streamline clinical trials via standardization through accreditation of REBs and development of the institution of the Board of Record, thus creating a mechanism for research institutes to recognize and accept the results of ethics review by a designated Boards of Record.
The Ontario Cancer Research REB is an example of a specialized board that reviews cancer clinical trials. It currently serves 26 of the 27 hospitals conducting such research. This is how OCREB reflects on the advantages it offers to participating institutions:

> OCREB's centralized model means that once a study has been approved by OCREB, additional study sites can receive OCREB approval within days. This minimizes redundancy and saves the time and cost of having the study reviewed by an REB at every participating institution. … In annual surveys, stakeholders have noted many advantages of OCREB over the single centre REB model, for example: high quality reviews; efficiency in the submission and review processes; ease of use and transparency of the online system; consistency in consent forms across all sites in the province; rapid approval times; clear communication; consistency in processes; and professional and knowledgeable staff. http://oicr.on.ca/oicr-programs-and-platforms/ontario-cancer-research-ethics-board.

In other words, a decentralized model has significant limitations in reviewing complex, multicentre studies. Tolich and Smith (2015) discuss the how the same limitations emerged in the devolution of ethics review in New Zealand following the Cartwright Inquiry, and the resulting formation of a multi-centre ethics review panel. These shortcomings of the devolved model are a consequence of a parochial understanding of research as an activity, limited to a particular institutional jurisdiction, and initiated by researchers affiliated with it, and working within its

walls. These assumptions, of course, map poorly on collaborative, multi-institutional, and transnational research initiatives.

It is worth noting that REBs themselves recognize these limitations and are actively engaged – directly and via professional associations – in (a) creating networks and 'evolving' from institutional REBs reviewing all institutional research to specialized REBs, (b) developing common standards, harmonizing ethics forms and standard operating procedures. Knowledge transfer occurs at various levels – municipal, provincial and national. For example, The Toronto Academic Health Science Network (TAHSN), comprised of the University of Toronto and 13 affiliated academic hospitals, has been using a standardized ethics review form. http://www.tahsn.ca Similarly, OCREB, the National Cancer Institute of Canada Clinical Trials Group (NCIC CTG), and the British Columbia Cancer Agency REB have been engaged in harmonizing their approaches to free and informed consent. Similar initiatives have taken place in other provinces.

Community-based REBs can be seen as yet another example of specialization. They emerged to fill the gap in non-institutional and non-academic research. TCPS and its counterparts in other countries influence the 'standard of care' for all researchers, even if they are not affiliated with academic institutions. Thus 'consent forms' may now be expected from community researchers, even if they are self-funded or unfunded. An increasing number of academic journals require a proof of ethics review and approval as a condition for publication. Neither in New Zealand, nor in Canada has any government or other policy articulated how the emerging institutional infrastructure for ethics review could be extended to non-academic and independent researchers. Yet there was a clear need as government and private researchers had no access to research review.

In New Zealand, former chairs of the dissolved Multi-region Health and Disability Ethics Committee acknowledged the shortcoming of the existing ethics review infrastructure by creating the New Zealand Ethics Committee to review research proposals from any researcher unable to access an institutional ethics committee. This initiative was motivated by the necessity to "move beyond a gatekeeping research governance function to that of bridge-building" (Marlowe & Tolich, 2015).

> The New Zealand Ethics Committee is a national ethics advisory committee, based in Dunedin, serving any researcher not eligible for ethics review from the standing institutional or health and disability ethics committees. Many research projects from professional, community and government researchers fall outside this narrow realm of health or university based research www.nzethics.com/

In Canada, one response, among others, has been the creation of *The Community Research Ethics Office*, an REB, serving Waterloo region and located in Kitchener, Ontario, is one of the ethics committees that emerged to facilitate community-based research http://www.communityresearchethics.com/ It sees its mission in terms of maintaining ethical standards in community based research, and has to speak the language of harm prevention used in TCPS 2:

> Research is increasingly being conducted by not-for-profit organizations, governments, independent consultants, community organizations, community researchers, and others. Unlike those institutions which have a Memorandum of Agreement with any of the three federal research agencies, community based researchers may not have access to institutional Research Ethics Boards. They are, however, still concerned with maintaining ethical research standards which help to ensure that no harm comes to those who choose to participate in their research. http://www.communityresearchethics.com/background/

Challenges in Transcending the Biomedical Framework and the Peer-review Model

Another important feature that characterizes the development of the system of ethics oversight is a continuous effort to transcend the existing peer review model, to engage non-scientific members in the ethics review of prospective research. Presumably this introduces an element of direct public audit, thus increasing transparency and social responsibly. This process has been rather challenging given a number of conceptual constraints, such as a positivist understanding of research as an activity done by scientific experts through disciplined inquiry and with intent of contributing to generalizable knowledge.

First editions of the Common Rule and TCPS make little emphasis on research as a social institution, on its role and function in society and its relations to the people in various capacities, including that of a primary stakeholder and collaborator. Within such a conceptual framework non-scientific members could hardly fulfil the function of independent (public) auditors, increase the transparency and accountability of research in humans, or contribute in a meaningful way to the development of ethical guidelines.

Earlier policy initiatives did not have a clear understanding of the role of non-scientific members on ethics committees. This is reflected in how these roles were rendered in policies and guidelines – *lay* and *non-scientific* members, *former research subjects/participants*, *non-institutional* and *community* members. Moreover, often there was an expectation that "external" members will be able to act in several capacities. For example, the requirements for 'community' members on the Interagency Advisory Panel on Research Ethics highlight the research participant perspective, which they understand in biomedical terms (Gontcharov, June 16, 2014). C*ommunity* members are generally recruited from the research community (e.g. retired academics) and are, in this sense, *internal* members (Gontcharov, June 16, 2014). Other groups of experts which could help to augment, if not transcend the scientific peer review model include bioethicists, experts in relevant methodologies and cultural variance, experts in health law and privacy, in addition to REB administrators as experts in the procedural aspects of ethics review (see also Gontcharov, June 16, 2014). Again, similar to community members, these expert groups have not been empowered enough to facilitate the opening up of the institution of ethics review (for example, experts in "qualitative" methodologies), or in some cases promoted the biomedical perspective (bioethicists, health and privacy law experts).

Regulatory Capture of the Social Sciences

In the past two decades there was a rapid expansion of the system of ethics oversight, which was capturing more and more disciplines, more and more types of research, including unfunded and self-funded, academic and community-based. The biomedical model of prospective ethics review was used as a standard. The social sciences and humanities became subject to the new ethics regime, which gave rise to multiple points of tension between prescribed and valid ethical practices in research in humans. The question is why the Canadian social sciences did not resist the "harmonized" ethics of TCPS 1? Or in New Zealand, why social scientists did not protest the entrenchment of the Health Research Council's biomedical standards in universities? And, while there have been various critiques of the biomedical standards application to the social sciences (Langlois, 2011; Israel, 2004; Tolich & Fitzgerald, 2006) why did not social researchers protest as a group when the consequences of 'ethics creep' (to use Haggerty's expression) or 'ethical imperialism' (Zachary Schrag's) became apparent? One of the reasons is heterogeneity of the social disciplines – they represent a methodological spectrum thus embracing structured experimental methods and more flexible contextual 'qualitative' research techniques. Another reason for the lack of resistance to the new ethics regime is a desire to appear more scientific, even at the cost of sustaining a new ethics bureaucracy.

As Will van den Hoonaard writes in the *Seduction of Ethics* – initially some social researchers thought that it will be possible to collaborate with their biomedical colleagues in designing a common set of rules which would speak to all disciplines, but it soon became obvious that the design stage is over, that the regulatory capture of the social sciences has already occurred. The hope for an independent regime, or real exemptions for certain methodologies or research subjects, was also rapidly disappearing. It was a moment of a growing rupture between ethics on the books (procedural ethics) and ethics in practice. Thus, it became necessary to explore the alternatives to prospective ethics review. This is also reflected in Will van den Hoonaard's work: in 2002 in the edited volume "Walking the Tightrope" the key question was whether we should proceed 'towards a separate structure of ethics review' (van der Hoonaard, 2002) "The Seduction of Ethics" raises a poignant question: "What are the possible alternatives to ethics review" (van den Hoonard, 2011)?

New Brunswick Declaration's Impact

Has the Declaration been noticed in the discursive field of the research ethics community? The answer is positive – for example, the Canadian Association of REBs had a special session at the CAREB National Conference in Calgary in April 2013, entitled the "Great debate: Be it resolved the Tri-Council Policy Statement is a good standard for which to review research in the social sciences and humanities" (cf. Tolich & Fergusson, 2014). Although the title reflects the position of the Association that the current 'one-size-fits-all' model is good enough for all research in humans, it is commendable that those who oppose it are invited to the table to share their views and concerns.

In the Great Debate, the pro-TCPS side was represented by Lisa Given and Laura-Lee Balkwill (of the Secretariat) and the opposite side by Will van den Hoonaard and

Kirsten Bell. It is worth highlighting the modes of argumentation since they help to understand how and why the regulators deflect the criticisms of social researchers. The debate focused on the past ten years and inquired whether policymakers succeeded in accommodating the recommendations of the "Giving Voice to the Spectrum" Report (2004).

According to the supporters of the current Canadian model – TCPS is effective in enabling ethical social research. Thus, Lisa Given suggested that there has been significant progress in relation to most of the Report's policy recommendations. For example, TCPS 2 speaks in a new language of human participants instead of subjects, and projects instead of protocols. Kirsten Bell agreed that there has been some progress in respect to policy recommendations, but emphasized that this does not address the question of the debate is TCPS is a good standard of ethical governance in the social sciences. Will van den Hoonaard offered the content analysis of the Policy which elevates the status of REB members and professionals, while conceptualizing researchers as the only responsible party for the success of the Policy of which researchers may have limited control and which may not even speak to the actual ethical challenges of social research.

What this debate brought to surface is that there emerged a large group of professionals who are content with the one-size-fits-all model and their new status above 'ethics', and who may not be interested in studying the substantive issues, including those engendered by the system of ethics review itself. One of the authors of this paper has argued elsewhere that the on-going re-articulation of TCPS in what sounds like the language of the social sciences may not be a sufficient and adequate response to address to the governance of social research. For example, the transition from the concept of human subjects to participants, without addressing the underlying issues, will merely create a new euphemism (Gontcharov, 2016). Moreover to the questions of relevance and implementation, we can now add an acute problem consisting in methodological pauperization of the social sciences, since researchers gravitate towards the methods 'sanctioned' by REBs.

Although the Declaration has indeed been noticed, its message has yet to translate into policy decisions in Canada. As we have seen in an earlier given example, regulatory innovation proceeds quickly when it is market-driven. Academic papers and independent declarations have limited efficiency when there is no immediate and documented threat to domestic and global economic markets. Accordingly, one of the approaches to triggering regulatory activism would be to render the ongoing methodological erosion of social scholarship in market. However, to render "methodological pauperization" in the social sciences in economic terms may not be suitable and/or welcomed by social researchers as a strategy of promoting social research. Nevertheless, it is possible to emphasize the impact of the Policy. What can be done now is to rearticulate the articles of the Declaration in terms of policy recommendations, while continuing to build capacity by including a plan for action.

Conclusion: Proposed Development of the New Brunswick Declaration

One of the central themes of the Ethics-in-Practice Conference in Dunedin was the New Brunswick Declaration, including Prof. van den Hoonaard's keynote, two subsequent workgroup discussions, and a number of papers focusing on the

problematic of the Ethics Rupture Summit – a widening gap between mandated ethics and ethics in research practice.

Indeed, the conference itself was designed to showcase an approach to ethics inspired by the New Brunswick Declaration. First, in contrast to numerous conferences for ethics professionals as venues for sharing administrative and management practices, or, the so-called, "research ethics 101" workshops by REB professionals for researchers on how to pass ethics review successfully by tailoring your application to procedural requirements, the Ethics-in-Practice Conference was envisioned as a platform for discussing (a) actual ethical challenges, faced by researchers on the ground, including the presence of embedded and alternative ethical systems, such those of indigenous populations, (b) scholarly research about the institution of ethics review and governance in research in humans.

Following discussions during the conference and workshops, and extensive email correspondence, participants agreed that the New Brunswick Declaration would benefit from further elaboration and refining of its principles and should set an immediate priority of improving relations between ethics committees and researchers. Endorsing this priority, we suggest below one of the possible ways to restructuring the articles of the Declaration to highlight this objective of cultivating trust in ethics review, thus supporting multiple actors, contexts and research methodologies, enhancing the ethical dimension in research in humans, and promoting critical scholarship and a broad discussion of regulatory innovation in the governance of research involving humans.

Article 1 (*Culture of Trust*) – emphasizes trust and mutual respect as a basis of research governance. Researchers and participants should be treated equally by ethics committees and policymakers.

Article 2 (*Collectivities and Individuals*) – the importance of collectivities, group interests and group consent in the governance of research involving humans, and the limitedness of risk management on the basis on individual harm.

Article 3 (*Professional Self-governance*) – the role of professional associations, professional self-governance and methodologically-relevant standards in the governance of research involving humans.

Article 4 (*Ethical Pluralism and Broad Governance*) – ethical and methodological pluralism, the role of existing institutions of peer-review, and the contribution of multiple actors, including the public, in the governance of research in humans.

Article 5 (*Experiential Learning*) – the importance of experiential ethics, contextual ethical education and academic apprenticeship.

Article 6 (*Bridges between Ethics Committees and Researchers*) – acknowledges the existing rupture between procedural ethics and ethics in practice.

Article 7 (*Freedom of Expression*) would emphasize the connection between academic research and freedom of expression, the importance of which is particularly important now when the institution of tenure is rapidly eroding.

Article 8 (*Evidence-Based Ethics*) – the need for evidence-based ethics and support of critical scholarship on the current models of ethics review and research governance.

Article 9 (*Consultative Governance*) – the benefits of consultative models over prospective ethics review.

Article 10 (*Research Beyond Academia*) – the interconnectedness of academic, independent and journalistic research.

Article 11 (*Declaration: Today and Tomorrow*) – the need for further development of the principles outlined in this Declaration.

Second, the conference was preceded by an indigenous welcome by mana whenua (people of the area) to appropriately locate the conference on their geography, under their Mana (power, authority), and within their kawa & tikanga (rules and customs). Moreover, kawa and tikanga were discussed within by the spokesperson for mana whenua within the context of the contribution by mana whenua to the governance of research in humans, within Otago, and their concerns and criticisms of the local process were raised.

Third, the opening plenary took place at the Otago Museum, allowing the participants to appreciate the richness of the cultural traditions of the area. In this plenary, Barry Smith, a prominent Maori scholar of ethics review, argued, on the basis of the a new book that he co-authored with Martin Tolich, for improved dialogue about the governance of research in humans in New Zealand, which would be evidence-based rather than driven by policymakers and REB professionals' considerations. As discussed above, these considerations are often dictated by the market, or are reflective of moral panics, and methodological preferences, rather than genuine interests in creating a safe environment conducive to the advancement of knowledge. This was a theme repeated and placed in a global perspective by both the second and third plenary speakers, Julie Bull and Martin Tolich respectively, and was a common thread of the entire conference, thus providing a rich and stimulating environment for developing The New Brunswick Declaration and proposing this concept of The 2016 New Brunswick-Otago Declaration on Research Ethics.

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