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## The Changing Research Data Landscape and the Experiences of Ethics Review Board Chairs: Implications for Library Practice and Partnerships

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## ABSTRACT

Academic libraries have to a large extent taken the lead in facilitating new approaches to research data management, but changes to the research data landscape have had an impact on numerous areas of academic work, including ethics review. Using interpretive phenomenological analysis of interviews with chairs of Canadian research ethics boards, this study explores how ethics review boards have experienced changes to data policy and related technologies in order to describe the ethical implications of new approaches to data management and to explore ways in which the library, ethics review boards, and other campus partners might harmonize efforts to support emerging data practices. While ethics review boards in Canada are keenly aware of open data policies, data publishing in practice is still nascent. There is uncertainty about the adoption of changing technologies for research and their impacts on privacy protection. Where responsibility lies for addressing these uncertainties is often unclear. Academic libraries and research ethics boards are well-suited to engage in mutual knowledge transfer and to integrate data management planning and ethics review processes. Institutional-level oversight that includes all campus departments impacted by changes to the research data landscape may facilitate improved communication and reduce role ambiguity.

### Introduction

The research data landscape is changing. Data management planning is becoming a more prominent step in the research process, while a growing list of funders and publishers have tied strict data archiving and open release requirements to their agreements with researchers. Driving the evolution toward better data management practices, in part, is a dynamic technological infrastructure. Researchers must see beyond research methodologies to consider how the devices and software they use will impact the collection, storage, security, publication, and disposition of their data. Without adequate thought to the technologies involved in a project, data may be suboptimal or inaccurate, accidentally lost or retained, inappropriately shared, published in inaccessible formats, or otherwise unfit for future use. Events such as these not only impact the outcomes of research, but may have serious ethical consequences, particularly when the data describe human subjects.

On-campus advocacy and support for research data management (RDM) and data publishing initiatives come from numerous departments, including libraries, research administration, information technology services, legal offices, and, of course, researchers, with librarians and research administrators most often taking the lead in promoting and supporting RDM (Cox, Kennan, Lyon, & Pinfield, 2017).

While there is potential for jurisdictional conflict where these services overlap (Verbaan & Cox, 2014), there is also potential for new partnerships. Adequate support for RDM requires expertise and resources from disparate campus departments, and the pooling of these assets will only benefit the larger community (Jones, Pryor, & Whyte, 2013).

This collaborative environment requires an understanding of the strengths and struggles of other campus units that support RDM. A sympathetic view of other campus departments can lead to the reconciliation of differing perspectives and more efficient achievement of shared goals (Latham, 2017). Much of the discussion to date around roles and perspectives in the RDM realm has focused on the policy and technology concerns of the library, IT, and research administration (Pinfield, Cox, & Smith, 2014). One area of concern that has been largely overlooked is research ethics.

Although ethical compliance often falls under the general purview of research administration, ethics review boards as a sub-group have received little mention, outside of ethics specific journals, with respect to their role in the changing research data landscape. This role is an important one, given the complexity of new data handling environments. The evolution of technologies for collecting, analyzing, and storing data and the push for open data raise questions about data security, participant privacy, and informed consent. These questions need to be considered by all campus partners involved in data management

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planning and infrastructure development. Ethics review boards, which are usually composed of experienced researchers and reviewers, are well-positioned to provide expertise in this area.

This study seeks to tap into that expertise by examining the experiences of ethics review boards at Canada's most research intensive universities. Using a phenomenological approach and semi-structured interviews, this study describes how eight chairs of ethics review boards have encountered changes to the research data landscape and how they perceive the ethical issues surrounding those changes. It is hoped that this research will contribute to a deeper understanding of the ways in which ethical compliance processes should be situated with respect to the work of librarians on data planning, management, archiving, and publishing, and help illustrate the role of ethics review in campus-wide research data management activities.

## Background

### *Ethics review and research data in Canada*

The human research ethics review process at Canadian universities is structured through a joint policy of the three federal research funding agencies, the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada (NSERC), and the Social Sciences and Humanities Research Council of Canada (SSHRC), often referred to as the Tri-Council or Tri-Agency. Institutions receiving Tri-Council funding are required to sign a memorandum of understanding to abide by the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (Canadian Institutes of Health Research, 2014), or the *TCPS 2*. The *TCPS 2* establishes the policy framework for institutional ethics review in Canada, including the structure of research ethics boards (REBs), as well as the scope, principles, and even some processes for ethics review. The *TCPS 2* applies to all human research occurring under the auspices of institutions that have signed the MOU, not just Agency funded research.

Questions of ethics that apply to the research data lifecycle are primarily covered in the chapter of the *TCPS 2* on privacy and confidentiality. In it, the document outlines expectations that researchers describe procedures for maintaining participant confidentiality and for safeguarding private research data against “unauthorized access, use, disclosure, modification, loss or theft.” It also places a very broadly-stated responsibility on institutions to develop safeguards that should include “adequate physical, administrative and technical measures, and should address the full life cycle of information.” According to the policy statement, then, responsibility for data security throughout its cycle is shared by the researcher and the institution.

The Tri-Council's *Interagency Advisory Panel on Research Ethics* (n.d.) has, since the original publication of *TCPS 2*, clarified its vision of stakeholder responsibilities through an interpretation of the chapter on privacy and confidentiality. In its interpretation, the panel places overall responsibility for safeguarding participant data and for anticipating potential data breaches on the researcher, with responsibility for review of the researcher's data security measures falling on the REB. The same interpretation expanded institutions' responsibilities to include “creating and maintaining a supportive research environment, establishing appropriate institutional security safeguards, training researchers and REBs regarding best privacy practices and implementing processes and policies that guide and support researchers and REBs in protecting participant confidentiality.” This structure places the REB in a role of gatekeeper (Cook, Snyder, & Calvert, 2015), in a position to observe trends in approaches to research data management and the degree to which institutions are meeting their policy obligations *vis-à-vis* infrastructure and training for data security.

REBs are also responsible for ensuring that privacy measures are communicated to participants through the informed consent process. Broadly, informed consent procedures are meant to establish the terms of participation - that it is fully voluntary with full knowledge of the

purpose, risks, and benefits of the research. With respect to data, the *TCPS 2* requires that participants be informed about the nature of the data that will be collected and the purposes of collection, who will have access to information about participant's identity, how confidentiality will be maintained, and the anticipated uses of the data.

The *TCPS 2* provides a big umbrella approach to ethics review but, as some critics have noted, it can be challenging for boards to consistently apply the document's principles across unique cultures and projects. As a result, REBs develop local rules and customs beyond what is recommended in an effort to ensure full compliance and consistent application of ethical principles within the institution (Bell, 2016; Schrag, 2010). Board members themselves may be unsure about what is required by policy and what is local practice (Cook et al., 2015). In some cases, identical research protocols sent to multiple REBs have received very different reviews (Warrell & Jacobsen, 2014), suggesting that the approach to ethics review in Canada is much more siloed than what is intended by the Tri-Council policy.

The significant responsibility for scrutinizing data management practices is not unique to Canadian ethics committees, of course. Speaking about American ethics boards, Hardy, Hughes, Hulen, and Schwartz (2016) noted that “one of the most difficult charges for IRB committees is the ability to anticipate a full range of potential conflicts or dangers that could result from improper data collection, storage, or maintenance, and to ensure that researchers develop plans to offset any risks from the outset of a project.” This is exacerbated by the continuous evolution of the technologies and methods of research, an evolution that has occurred while the protocols used to protect participants largely have not changed (Buchanan & Ess, 2009). Reviewers are faced with the challenge of applying broad ethical principles to projects that include complex and fluid tools for data collection, storage, and security, while limited training resources for boards tend to be devoted to general research ethics rather than specific technological challenges (Buchanan & Ess, 2009).

### *Ethics and new data environments*

How research data are collected, stored, shared and destroyed is heavily impacted by evolving technological, methodological, and philosophical approaches to research. These changes naturally raise questions about the suitability of the existing ethical framework within a complex landscape. This section will outline some of those questions.

Internet-based data collection has complicated ethics review by blurring lines between public and private information. In 2008, a working group of the Interagency Advisory Panel on Research Ethics, noting gaps in the first iteration of the *TCPS*, made a number of recommendations in order to address concerns around internet research, including differentiating between non-intrusive data collecting and participatory human research, as well as outlining requirements that researchers announce themselves and obtain consent when gathering data from online spaces where there is some expectation of privacy, such as chat rooms (Social Sciences and Humanities Research Ethics Special Working Committee, 2008). While the *TCPS 2* did fill some gaps around the scope of ethics review with regard to Internet research, it has been criticized for failing to address other complexities of Internet research, including recruitment, estimating risk, and informed consent (Warrell & Jacobsen, 2014).

More recently, issues around consent and privacy have been raised in the context of big data analytics involving human data. Metcalf and Crawford (2016) note that, because the field of data science stems from disciplines such as mathematics and computer science that have traditionally been removed from human research, the use of human data collected from Internet sources by data scientists presents new challenges for both researchers and ethics review boards more accustomed to behavioural research. As there are few existing frameworks for the ethical handling of large datasets about people, researchers in the discipline are grappling with issues of risk and re-identification, and

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