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February 17, 2017

Dr. David Morgan
PHIA Review Chairperson
c/o Department of Health and Community Services
Confederation Building
St. John's, NL A1B 4J6

Dear Dr. Morgan:

Please accept this submission to the PHIA Review Committee by Memorial University.

As you know, four of Memorial's academic units are named in Section 4(1)(j) of the *Personal Health Information Act (PHIA)* as custodians. The four named academic units are the Faculty of Medicine, School of Human Kinetics and Recreation, School of Nursing and School of Pharmacy. Memorial University has made several requests to Government in the past (2011 and 2012) to not have those units named as custodians in PHIA. The basis of the request is outlined again below for your consideration. Memorial University would welcome the opportunity to clarify any points for the Committee.

At the outset, it is helpful to understand Memorial's purpose as the sole university within the province. Section 3(3) of the *Memorial University Act*, RSNL 1990, c. M-7, establishes this mandate as follows:

- "3. (3) The university shall have full power and authority to establish and maintain those faculties, colleges, schools, institutions, departments, chairs and courses that may seem appropriate to the board, and
- (a) to give instructions and training in all branches of knowledge and learning, including physical instruction and training;
 - (b) to grant degrees, including honorary degrees, diplomas and certificates of proficiency;
 - (c) to provide facilities for the prosecution of original research in every branch of knowledge and learning and to conduct and carry on that research work; and
 - (d) generally, to promote and carry on the work of a university in all its branches."

As the above makes clear, Memorial's primary functions are education and research. The delivery of health care services does not fall within Memorial's mandate. It is true that several units at Memorial deliver health care services, namely the Student Health Clinic, the University Counselling Centre, the Family Medicine Practice, the PsyD Clinic, and the Medication Therapy Services clinic; however, these are services delivered to members of the Memorial community and not as part of Memorial's educational or research mandate. As such, it is appropriate that these individual units be considered custodians for the purpose of PHIA. Each such unit is actively engaged in ensuring compliance with that legislation.

Central to the issue of whether it is appropriate to bring Memorial's four faculties at large within the scope of PHIA is whether doing so is necessary to enable the objectives of that legislation to be met in a way that

ensures the burdens it imposes are offset by its benefits. Memorial submits that removing its four faculties from the definition of “custodian” would have little, if any, impact on the fulfillment of the purposes identified in section 3 of the statute; however, continuing to include the faculties in the definition, and continuing to impose PHIA on Memorial, creates many potential problems within both the teaching and research contexts. These problems are discussed further below.

Teaching and Learning

Many PHIA custodians, particularly Eastern Health and other regional health authorities, benefit from and share the university’s mandate of educating health care professionals by providing students with opportunities to work in clinical settings. The students are located on the premises of these custodians, sometimes as part of the “circle of care”. Given that the students are participating in such activities in an educational capacity, it is logical for them to be considered part of the Memorial community. However, such circumstances create the potential for confusion as to which organization is ultimately responsible for the student’s activities and sets up the possibility of conflict between the policies and procedures of the respective organizations.

Memorial and these other organizations have evolved an approach to address such issues. While on the premises of such other organizations or conducting activities on their behalf, it is expected that students will comply with the policies and procedures of those other organizations. Further, such organizations generally reserve the right to place limits/restrictions on student placements, up to and including their termination. These points are often explicitly set out in affiliation agreements between health care organizations and Memorial. As such, students who obtain access to or use of personal health information while on the premises of such organizations do so on behalf of the organization and not Memorial, often as part of a patient’s circle of care and under the supervision/authority of the attending practitioner who is the responsible member of the circle of care. Students are not permitted to leave the organization with any personal health records in their possession, as such records belong to the organization and are the responsibility of that custodian.

In light of the above, imposing PHIA on Memorial to ensure the security of personal health information obtained by Memorial students is unnecessary and duplicates administrative requirements. Indeed, to date students have been required by both Memorial and health care organizations such as Eastern Health so sign separate oaths of confidentiality, even though the oaths relate to information that is to be accessed and used by the students only on the premises of the organization.

In addition to the confusion created in PHIA by naming Memorial’s four faculties as “custodians”, the current PHIA Regulations are problematic. The Regulation provides at section 3 as follows:

“3. Where a custodian has entered into an affiliation agreement to provide instruction to a student or other person in his or her course of study to become a health care provider or a health care professional, that instruction is a health care service within the meaning of paragraph 2(1)(h)(viii) of the Act.”

First, since not all custodians that accept students for work placements have entered into affiliation agreements with Memorial, this Regulation creates potential for PHIA to apply differently to students and/or Memorial depending upon the ultimate location of the student’s work placement.

Second, it is not clear if the intention of the Regulation is to make students “health care providers” or “health care professionals” for purposes of the statute or instead to ensure the Memorial faculty in which the student is enrolled is to constitute a “custodian” under the legislation. Advice to Memorial by the Department of Health and Community Services indicates that the Regulations permit custodians to “disclose” personal health information to students, an interpretation that transfers responsibility for the care of patient information from the custodian to a student or to the university. However, we submit that patient information is better protected if the student is acting on behalf of the health care organization during a work placement with such organization. Indeed, this approach is reflected in Ontario’s Personal Health Information Protection Act (on which PHIA is modelled). Section 37(1)(e) of that statute states:

“37(1) A health information custodian may use personal information about an individual:

...

(e) for educating agents to provide health care. “

Memorial University submits that PHIA should be amended to ensure students in work placements are regarded as agents of the custodians with whom they are placed, as this reflects the principles and intent of existing affiliation agreements and arrangements in place between Memorial and such custodians. Moreover, it would reduce confusion about roles and responsibilities for the protection of patient information.

The overlapping roles of individuals who are cross-appointed between organizations such as Eastern Health and the Faculty of Medicine are likewise inadequately addressed by the current state of PHIA. Where such individuals obtain access to or use of personal health information about identifiable individuals (patient information), they do so either in the context of clinical work or university research. Where individuals obtain such access as part of the circle of care, they are not acting in their capacity as a faculty member but rather as a health care professional, either in their own capacity or on behalf of a health authority. As such, their access to and use of personal health information should be subject to the control, direction and policies of the applicable health authority or provider of health care services. As is the case with university students, existing affiliation agreements between Memorial and health authorities reflect this principle. Where instructors wish to obtain access to personal health information for university research purposes, they must first obtain the consent of the health authority or other provider of health care services and obtain requisite ethics clearances.

For all of the above reasons, Memorial submits it is inappropriate, in light of the historical practices of and current teaching arrangements in place between Memorial and health care organizations, to apply PHIA to Memorial's four named faculties. Doing so creates unnecessary administration and confusion and, accordingly, may actually serve to heighten the risks to the security of personal health information that are intended to be mitigated by the legislation.

Research

Memorial researchers frequently collect and use research data that may meet the definition of "personal health information" set out in *PHIA*; however, in academia, such research data has historically been subject to the oversight of ethics boards and safeguarded by conditions they impose. Indeed, health researchers are legally required to obtain ethics approval and meet ethics conditions pursuant to the *Health Research Ethics Authority Act*. Accordingly, applying PHIA to such research data and Memorial's researchers unnecessarily duplicates both legislative requirements and existing ethical requirements imposed by bodies such as the Tri-Council Agencies (made up of 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)). Memorial submits such duplication is particularly unwarranted in light of the way in which the legislation potentially creates various impediments to research and the development of intellectual property and undermines existing practices in academia around research data custody and control.

Academic freedom is key to ensuring the robust advancement of research. It is a principle sedulously fostered at Memorial. In its Policy Statement on the subject, the *Tri-Council* states as follows:

"Significant advances in human understanding in the social sciences, humanities, natural sciences, engineering and health sciences have been made as a result of research involving humans. A fundamental premise of this Policy is that research can benefit human society. In order to maximize the benefits of research, researchers must have academic freedom. Academic freedom includes freedom of inquiry, the right to disseminate the results of that inquiry, freedom to challenge conventional thought, freedom to express one's opinion about the institution, its administration or the system in which one works, and freedom from institutional censorship. With academic freedom comes responsibility, including the responsibility to ensure that research involving humans meets high scientific and ethical standards that respect and protect the participants. Thus, researchers' commitment to the advancement of knowledge also implies duties of honest and thoughtful inquiry, rigorous analysis, commitment to the dissemination of research results, and adherence to the use of professional standards. There is a corresponding responsibility on the part of institutions to defend researchers in their efforts to uphold academic freedom and high ethical, scientific and professional standards." [Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, December 2010.]

In order to safeguard academic freedom, it is imperative that the trust relationship between a researcher and his or her research subject is protected. This generally requires ensuring that information entrusted to the researcher is not divulged to others outside the relationship. Indeed, this concern is recognized by the Tri-Council Policy, which cautions against putting researchers in the position of "informants for authorities or leaders of organizations". The concern is also reflected in section 18 of the *Statistics Act*, RSC 1985, c. S-19, which expressly exempts Statistics Canada researchers from being compelled to testify or produce information in a proceeding. Imposing *PHIA* on research data would therefore potentially create an obstacle to the academic freedom of Memorial's researchers insofar as it would potentially expose this data to the investigative and disclosure powers of the Information and Privacy Commissioner and to the types of mandatory disclosures set out in sections 41(1), 42(1) and 43. It is worth noting, for example, that in at least one recent court case, a claim of academic freedom by researchers at the University of Ottawa was sufficient to ground the quashing of a search warrant for research information in their possession (see *R. v. Magnotta*, 2014 QCCS 132). Section 41(1)(b) would potentially preclude a Memorial researcher from successfully advancing a similar position with respect to research data that meets the definition of "personal health information".

Further, because they are guaranteed academic freedom, academic researchers should not be regarded as being under the direction and control of their employer to the same degree as an employee who does not enjoy such freedom. Researchers at Memorial who are guaranteed academic freedom are generally regarded as having custody and control of research data they collect. Again, it is worth referring to the policies and principles of the *Tri-Council* and, in particular, section 2.1.2 of the Tri-Council's Framework on the Responsible Conduct of Research, which makes individual researchers responsible for "keeping complete and accurate records of data, methodologies and findings" (section 2.1.2(b)). *PHIA* does not currently reflect this principle and instead assumes that the institution is the actual custodian of such data.

Subjecting research data to *PHIA* also potentially creates impediments to research generally by imposing obligations on researchers at Memorial that are not imposed on researchers in private industry in the province (and elsewhere) or on other institutions with which Memorial collaborates. By way of example, *PHIA* grants to individuals various rights of access and correction to their personal health information (see, for example, sections 52 and 60). These rights are not afforded to individuals who participate in research projects undertaken by private industry within the province or any researchers outside the province. At best, this imposes an administrative burden on Memorial's researchers that is unnecessary and makes research collaborations with extra-provincial institutions more difficult. At worst, it creates an un-level playing field between researchers at Memorial and those in private industry.

Aside from impeding academic freedom and potentially slowing research, applying *PHIA* to research data could also threaten the commercial viability and value of intellectual property generated in the course of such research. Research data is extremely valuable, particularly where such data is acquired from a distinctive genetic population such as that found in Newfoundland and Labrador. As such, subjecting such data to the forms of mandatory disclosure set out in *PHIA* could threaten its intellectual value. Indeed, it is important to note that research is specifically excluded from the scope of the province's *Access to Information and Protection of Privacy Act, 2016* for this very reason. This exclusion of research reflects the unique niche that research occupies in institutions of higher learning and respects long-standing principles of competitiveness and intellectual property rights. Similar exclusions are found in similar access and privacy legislation across Canada.

For all of the above reasons, Memorial submits that applying *PHIA* to research data creates unnecessary confusion and could violate various principles intrinsic to the proper functioning of an institution of higher learning. We note that Ontario's *Personal Health Information Protection Act, 2004*, S.O. 2004 c.3, Sch A, on which *PHIA* is based, does not name universities or academic units as custodians, thus avoiding the complications imposed by *PHIA*. Memorial submits that the same approach is warranted in this province.

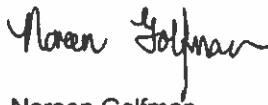
Summary

PHIA is designed to protect personal health information and support health care, planning and monitoring of the health system, public safety and health research. It codifies roles and responsibilities of custodians. Maintaining academic units as *PHIA* custodians is an inaccurate representation of their role. As stated, those units of Memorial University which deliver health care services as part of a circle of care have been and will continue to comply with *PHIA* and any other applicable legislation. As the Act does not list all custodians in the province, but rather includes them by whether or not they meet the definition, it is Memorial University's request that its four

academic units (Medicine, Pharmacy, Nursing and Human Kinetics and Recreation) cease to be named as custodians in the Act.

Thank you for your consideration. We would be pleased to provide additional information or clarification.

Sincerely,



Noreen Golfman
Provost and Vice-President (Academic)



Ray Gosine
Vice-President (Research) *pro tempore*

cc Dr. G. Kachanoski, President
Dr. M. Steele, Dean, Faculty of Medicine
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