



SAFEGUARD

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OIPC Outreach to Custodians

OIPC reached out to custodian groups, such as regulatory bodies and advocacy groups, by email on April 21st offering education sessions and consultations. If you did not receive the email and/or are interested in a training session or consultation opportunity, please contact our office at 729-6309 or commissioner@oipc.nl.ca

In accordance with the *Personal Health Information Act (PHIA)*, custodians are obligated to develop policies and procedures on how custodians and employees collect, protect, use, and disclose personal health information of its patients and clients. While the OIPC cannot train on the specific policies and procedures of an individual custodian, we can train on the fundamentals of *PHIA*, and review existing policies and procedures and offer recommendations on how to strengthen these protocols.

This is one of our proactive advocacy activities to assist custodians with *PHIA* compliance. OIPC has also developed a number of resources to assist with *PHIA* compliance, available on our [website](#).

Annual Meetings – Making Privacy a Priority

Although there are many touchpoints throughout the year, OIPC makes a special effort to meet annually with several of the large custodians, including the Regional Health Authorities and the Newfoundland and Labrador Centre for Health Information. We use these meetings to remain up-to-date on the activities of the custodian, discuss any privacy or access related challenges and to hear the creative solutions being identified to address challenges. This year's meetings have concluded and OIPC was pleased to see that,

even during this extended public health emergency, these entities are staying on top of access and privacy issues.

OIPC noted that many entities reviewed current policies and either updated or developed new policies; collaborated with each other to leverage existing tools; continued to keep *PHIA* expectations top-of-mind, including staff training and the signing of the Oath/Affirmation; conducted privacy assessments of new or changed programs; worked to develop a streamlined research approval process; and developed new tools to assist with *PHIA* compliance.

The theme for Privacy Awareness Week, held during the month of May, was Making Privacy a Priority. The meetings demonstrated the ongoing commitment the RHAs and NLCHI have to privacy and access issues and we thank them for all their efforts.

The Role of Organizational Approval in the Health Research and Evaluation Regulatory Journey

Guest Column by:

Dr. Farah McCrate, Director, Research and Innovation at Eastern Health and Co-chair, RPAC

The need for ethical oversight in the conduct of research is generally well understood by health researchers. The [Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans](#) (current iteration: TCPS 2 (2018)) is a joint policy of Canada's three federal research agencies. This Policy expresses the agencies' commitment to the people of Canada to promote the ethical conduct of research involving humans. In NL, the provincial Health Research Ethics Board (HREB) has been established through legislation (the [Health Research Ethics Authority Act](#)) by the [Health Research Ethics Authority](#) (HREA) to fulfill this function. The mandate of the HREB is to review health research involving human subjects that is being conducted in the province.

Although potentially less well known or understood by the research community, there is also a role for organizational review and approval in the health research regulatory journey. For Regional Health Authorities (RHAs) in NL, including Eastern Health, organizational review is instrumental in ensuring that privacy considerations and resource implications are considered. The committee that reviews health research at Eastern Health is named the Research Proposal Approval Committee (RPAC). Common misconceptions about RPAC include the perception that it functions as a 'secondary ethics process' or that HREB approval 'trumps' organizational approval, meaning if HREB approval is granted, organizational approval should seamlessly follow. The reality is that these two review and approval processes are distinct and governed by different, but complementary, pieces of legislation. While the HREB review process is governed by the HREA Act, organizational approval is, in part, governed by the [Personal Health Information Act \(PHIA\)](#).

In brief, the mandate of RPAC is to review research proposals that propose to: a) access data for which Eastern Health is the custodian, b) impact Eastern Health resources in the conduct of research, and / or c) recruit participants or conduct research at an Eastern Health facility. To fulfill its legislative obligations under *PHIA*, RPAC requires that appropriate processes are in place for the collection, use, disclosure, protection, storage, retention and destruction of personal health information. Additionally, RPAC assesses impact on Eastern Health resources

and determines the requirement for compensation and/or management. All research reviewed by RPAC must first have approval from the HREB or other duly constituted research ethics board.

While the mandates of the HREB and RPAC are different, some of the information required for ethical review is also required for organizational review. As such, the HREB, RPAC, the RHAs, and the NL Centre for Health Information (NLCHI) have seized upon the opportunity to streamline processes and identify efficiencies.

To this end, representatives from all of the above-named organizations have come together to collaborate on finding ways to simplify and demystify research approval while still ensuring that legislative and organizational requirements are upheld. One major advance is the development of an organizational application form that is common across these organizations of health data. This removes the burden of having to complete, depending on the scope of the project, up to five different organizational approval forms. A centralized intake process has also been established that, while not mandatory, is available for researchers requiring assistance identifying and navigating data sources. This service is provided by NLCHI on behalf of all the RHAs.

In the case of Eastern Health specifically, the RPAC has made additional process improvements including increasing its meeting frequency from monthly to bi-weekly to better align with the HREB review schedule. Committee members have also overseen the development of an overarching data sharing agreement between Eastern Health and Memorial University. This provides an assurance that appropriate data sharing and management will occur when data for which Eastern Health is the custodian are requested by Memorial University affiliated researchers. Additionally, it removes the administrative need to execute a separate data sharing agreement every time a Memorial affiliated project is reviewed, while still ensuring that Eastern Health's terms and conditions are clear and agreed to by the researcher(s).

A final noteworthy initiative undertaken by Eastern Health is related to the conduct of evaluation by parties external to the organization. The newly created Evaluation Proposal Approval Committee (EPAC) engages in a review process for evaluation projects that closely mirrors that for research. Because projects deemed evaluation do not require HREB approval, they come directly to EPAC for review. This evaluation review process has addressed a critical gap in non-research related data governance and management. The truth is, oversight of how personal health data are managed is equally important whether those data are being accessed for the purposes of research or evaluation.

Information and guidance about Eastern Health's research and evaluation review processes can be found by accessing the following link: <https://ri.easternhealth.ca/> or by emailing rpac@easternhealth.ca or epac@easternhealth.ca.

APSIM Conference a Success!

The Access, Privacy, Security and Information Management (APSIM) conference, originally scheduled for last year, proceeded as an online event from March 16-18 with a mix of live and pre-recorded presentations and talks. Over 250 participants registered for this event.

Conference highlights included: keynote addresses from University of Ottawa Faculty of Law professor Dr. Teresa Scassa on the future of privacy in Canada and former British Columbia Information and Privacy Commissioner David Loukidelis on developments in privacy and access

laws and digital economies. There was both a Coordinators Panel and a Regulators Panel, providing insight into the roles played by both parties. Other conference highlights include presentations on passwords and protecting yourself online, cloud computing, online safety, managing shared drives, digital government, and data governance in healthcare.

In the coming weeks, we hope to be able to make some of the conference presentations and other resources available at <https://www.gov.nl.ca/apsim/>.

We continue to offer this biennial conference at no cost to participants, in an effort to grow our common communities. Online conferences also remove travel barriers, increasing accessibility for custodians outside of the St. John's area. If you have feedback on this conference or suggestions for future conferences, please contact commissioner@oipc.nl.ca. If you attended and haven't yet completed our survey, please take a minute to help us shape future events by completing it now; the survey consists of 10 questions and should take only 2-3 minutes to complete:

<https://www.surveymonkey.com/r/72X7Z8C>

This conference would not be possible without the support and involvement of the local access, privacy, security and information management communities. We'd like to thank everyone who worked collaboratively, pooled resources and delivered an outstanding conference with quality content. This conference was presented in partnership with Memorial University and its conference services through the Signal Hill Campus. We'd like to thank all presenters, members of the steering committee and staff at the Signal Hill Campus for making APSIM possible.

OIPC Podcast - Duty to Discuss

As part of its mandate to advocate on access and privacy matters, the OIPC recently created a podcast entitled "Duty to Discuss"; our second podcast is now available! In episode 2, Commissioner Michael Harvey chats with OpenMedia Digital Rights Campaigner Bryan Short about a number of hot-button topics, including Bill C-11, COVID-19 Exposure Apps, vaccine passports, and facial recognition.

To listen to Duty to Discuss, please visit our [podcast page](#) or search for the podcast on [Google](#), [Apple](#), or [Spotify](#)

Complaints and Breach Notifications

Between February 26 and May 26, 2021, the OIPC received the following breach notifications and complaints related to *PHIA*:

- Eleven breach notifications were sent to this Office following an incident. The majority of these breaches occurred within the regional health authorities.
- The OIPC received nine complaints related to *PHIA* during the same period of time; seven privacy complaints and two access/correction complaints.

Per section 15(4) of *PHIA*, material breaches – inappropriate collection, use, or disclosure of personal health information – must be reported to the Commissioner via the [breach reporting form](#) from the OIPC.