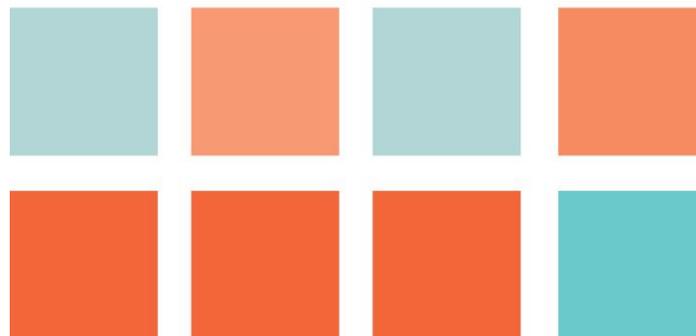


**RNAO comments on amendments to
PHIPA General Regulation and
development of HIPA regulations**

Submission to Health System Information
Management Division, Ministry of Health
and Long-Term Care

September 12, 2017



Introduction

The Registered Nurses' Association of Ontario (RNAO) is the professional association representing registered nurses (RN), nurse practitioners (NP), and nursing students in all settings and roles across Ontario. Since 1925, RNAO has advocated for healthy public policy, promoted excellence in nursing practice, increased nurses' contributions to shaping the health system, and influenced decisions that affect nurses and the public they serve. It is the strong, credible voice leading the nursing profession in Ontario.

RNAO appreciates the opportunity to provide feedback to the Health System Information Management Division of the Ministry of Health and Long-Term Care on the proposed amendments to the *Personal Health Information Protection Act*, 2004 (PHIPA) and policy directions for regulations under *Health Information Protection Act*, 2016 (HIPA).

We support initiatives to improve access to key health information at the point of care so health professionals can provide more coordinated, person-centred care.¹ However, we urge you to address the following concerns as you move forward with drafting regulations.

Opting out of the electronic health record

Under the proposed legislation, it is not clear whether a person can completely opt out of having an electronic health record (EHR). While all efforts should be made to promote participation in an EHR as it will improve care and strengthen data quality, some individuals may prefer not to have their personal health information (PHI) stored in this format. Although some may use consent directives to restrict access to all information except for the minimum list of non-maskable elements, this is not a substitute for having the choice to opt of the provincial EHR entirely. This option should be available.

It is important that the government provide an explicit rationale regarding why the collection of this personal information is necessary, and work to remedy any concerns that the public may have about participation in the EHR.

Non-maskable elements

RNAO believes that name, birth date, and an Ontario health card identification number (or an alternative identification number, e.g. Canadian Forces Health Care Identification card) are sufficient information to positively identify patients. We recommend that sex and address be removed from the list of non-maskable elements. RNAO has a proud history of advocating for health and human rights by increasing gender inclusivity.² For example, we welcomed gender-neutral health cards with a person's sex omitted. The inclusion of sex as a non-maskable element may discriminate people based on their gender identity and expression.³ We also recommend that a person's address be removed from the list of non-maskable elements to protect the safety of people who are at risk of violence.

Consent directive granularity levels

RNAO supports the five granularity levels – global, domain, agent, HIC-Agent, and HIC-Records – that are proposed. We suggest considering the addition of date-range granularity to allow patients to restrict access to their health information for a particular time period. For instance, an individual with a history of temporary psychosis may wish to mask all information related to this episode. Without a date-range option, it would be difficult for this person to navigate through the proposed five granularity levels and be confident that all information related to that episode is hidden.

Consent directives and consent directive overrides

In exceptional situations it may be necessary to temporarily override a consent directive, for example, in the event of a life-threatening emergency. Ontarians deserve to have their sensitive health information accessed by the fewest number of people necessary to deliver effective care. To maximize protection of PHI in an override situation, only those in the immediate circle of care should have access to the patient's PHI.

Notice of consent override should, at a minimum, specify the following: date of override, time of override, name of provider and health information custodian (HIC) involved in the override, and type of override. Contact information for the relevant individual at the HIC, as well as the contact information for the Information and Privacy Commissioner (IPC), should also be included in the notice of consent override.

We are concerned about a situation in which the health information custodian (HIC), who in proposed legislation has the responsibility to notify a patient about an override, does not provide notification of an override to the patient. RNAO recommends that the regulations lay out a clear timeline for notification and consequences for failing to notify. We also recommend that the prescribing organization – and not HICs – be responsible for sending out notification of overrides.

RNAO recommends that patients be able to specify their preferred contact method (e.g., text, email, via online portal) to be notified of consent override or unauthorized collection of data. This is necessary to maintain confidentiality; individuals may not tell others that they have masked a portion or all of their health information and RNAO believes that it would be a breach of their privacy to receive a letter in the mail that anyone in their household could open.

Security of personal health information

Robust security mechanisms must be in place to prevent intentional and accidental breaches in confidentiality. We understand that there may be instances of unauthorized collection of data. In these instances, RNAO agrees that the patient whose PHI was compromised must be notified. The notification process must be clearly delineated in the regulations (e.g., timeline for notification, sanctions imposed if notification is not provided). We recommend that the prescribing organization be responsible for sending out notification of unauthorized collection of data.

We also support mandatory reporting to the IPC when a privacy breach occurs, such as in an instance of unauthorized collection of PHI. RNAO also urges that IPC be empowered to respond to privacy breaches that are reported.

Education for patients, the public, and health-care providers

Protection of health information is complex. RNAO believes that it is essential that there is a plan in place to educate patients, members of the public, and health-care providers about electronic health records.

Education for patients should, at a minimum, include the following: what information is being held in the EHR; what security measures are in place to protect their information; how their information will be collected, used, and disclosed; that this is separate from the electronic personal health information held by their primary care provider (i.e., in an electronic medical record); what the Ministry of Health and Long-Term Care does with this data; the process to provide consent directives to mask all or portions of their information; circumstances under which consent directives may be overridden; and all potential consequences of masking information including risks.

Patients, members of the public, nurses, and other health-care providers should all be involved in the development of education materials and decisions about how patients manage their masking settings (e.g., through an online portal, over the telephone, etc.).

Health-care providers must all receive training on their obligations under this new legislation. RNAO urges the government to initiate a discussion with stakeholders about how to ensure that health professionals receive the education they need to understand the implications of this legislation. RNAO would be pleased to participate in this discussion, and to bring the perspective of RNs, NPs, and nursing students.

Patient control over their own health records

RNAO believes that all Ontarians should have control over and easy access to their own personal health records. A key component of person-centred care is to put patients - and in cases where patients consent, their family and/or caregivers - in control of their own health records, so that they can make informed decisions and more fully participate in managing their health care. PHIPA gives patients the right to see their own health information; however, this is currently an onerous and potentially expensive process. Ontarians do not have access to their EHR through eHealth Ontario.⁴ We urge you to provide patients with secure online access to their personal health information contained in their EHR.

¹ Registered Nurses' Association of Ontario (RNAO). (2016). RNAO submission on Bill 119: *Health Information Protection Act, 2015*. Submission to the Standing Committee on Justice Policy. Toronto: Author. Retrieved from http://rnao.ca/sites/rnao-ca/files/RNAO_Submission_Bill_119_3_2_16_FINAL_TL_2_1.pdf.

² RNAO. (2007). Position statement: Respecting sexual orientation and gender identity. Toronto: Author. Retrieved from http://rnao.ca/sites/rnao-ca/files/storage/related/2486_Respecting_Sexual_Orientation_and_Gender_Identity.pdf.

³ Ontario Human Rights Commission. (2014). Policy on preventing discrimination because of gender identity and gender expression. Toronto: Author. Retrieved from <http://www.ohrc.on.ca/sites/default/files/Policy%20on%20preventing%20discrimination%20because%20of%20gender%20identity%20and%20gender%20expression.pdf>.

⁴ eHealth Ontario. (n.d.). Accessing your EHR. Retrieved from <http://www.ehealthontario.on.ca/en/ehr/accessing-your-ehr>.