



November 15, 2019

Melanie Fraser
Digital Health Division
Associate Deputy Minister, Health Services
Ministry of Health
Melanie.Fraser@ontario.ca

Dear Melanie Fraser:

Re: PHIPA Modernization

We appreciated receiving the Ministry's document on PHIPA Modernization at the September 30, 2019 meeting of the Coalition of Ontario Regulated Health Professional Associations (CORHPA). All midwifery practice groups in Ontario are health information custodians under the Personal Health Information Protection Act (PHIPA); midwives as primary care providers are thus agents under PHIPA. The Association of Ontario Midwives represents registered midwives and Indigenous midwives across the province.

We are very supportive of actions that seek to enable greater access to timely comprehensive health care for patients and that also empower patients through access to their own personal health information (PHI). However, we would like to share with you a few serious concerns about the proposed modernization plan.

Informed choice is the basis of the model of midwifery practice in Ontario. Within this model, like other models of patient-centered care, the client is empowered to make the decisions that they deem are best for them and their baby. Midwives build a relationship of trust with their clients, provide evidence-based information and professional opinions, and participate in shared decision-making with their clients. The majority of our questions and comments in this letter centre on the process and the integrity of informed choice for clients/patients:

- It is important to consider that while many patients will be enthusiastic about various health care providers accessing their data with greater ease, some patients who may have a more complicated or stigmatized health or social history may fear discrimination based on their health history and may wish to opt out of having their PHI accessible to a broader network. An opt-out option must be available to all patients within a modernized PHIPA framework.
- Since sharing personal health information broadly throughout the system is new and was not explained to patients when their data was collected, we feel strongly that any new use for the data (including the sharing within Ontario Health Teams or more broadly within the system) would require a patient's informed consent prior to their historical personal health information being shared.
- The AOM is strongly opposed to the release of patient identifying data to the Ministry of Health, or any branch of the government. Midwives and their clients will have grave concerns with the Ministry of Health, or any branch of government, having access to all the personal health information of Ontarians regardless of the internal ministry process and best intentions to de-identify data.

Midwives have experienced this reticence to share information with an arms-length government agency first hand: midwives have received requests from clients to not enter their information in the Better Outcomes Registry Network (BORN) as they do not want their personal health information, or that of their newborn, to be accessible to those outside their circle of care. Healthcare providers should not have to choose between respecting their patients' choices about the sharing of their health information and the provision of care.

Some Ontarians may be reluctant to access health care or to divulge information to their healthcare providers for fear of discrimination by government agencies. The most serious repercussion of providing personal health information to the provincial government, is that patients may not access needed health care, share their full medical history, or may seek anonymous health services (e.g. anonymous HIV testing). Patients who need treatment for or have had a history of drug and alcohol addictions, mental health illnesses, sexual abuse, abortions, or sexually transmitted infections such as HIV, are most vulnerable in this regard.

Thank you for this preliminary opportunity to provide feedback. We look forward to reviewing the draft regulations when they are released. Should you have any questions, please do not hesitate to contact us.

Sincerely,



Elizabeth Brandeis, RM, BHSc, MScCH
President



Kelly Stadelbauer, RN BScN MBA
Executive Director