



MEMORANDUM

CL-C 22-2020

Subject: Collection, Use, and Disclosure of Personal Health Information

Related to COVID-19

Date: May 21, 2020

To: Regional Council

From: Ann-Marie Norio, Regional Clerk

The purpose of this memorandum is to provide information respecting current privacy legislation in Ontario and its impact on the disclosure of personal information and personal health information by Niagara Region.

The health and safety of Niagara's residents is of primary concern during the COVID-19 world-wide health crisis. Niagara Region Public Health (NRPH), in its efforts to significantly limit the spread of the virus is collecting appropriate personal health information about a significant number of individuals over a prolonged period of time. This sensitive information is being leveraged to trace contacts, to contain outbreaks and to gain insight about the virus itself and the threat it presents, which regularly changes based on the continuous flow of new information.

NRPH collects this information under the authority of the *Health Protection and Promotion Act* (HPPA) and in accordance with directives issued by the Province of Ontario through orders made under the *Emergency Management and Civil Protection Act*. Both pieces of legislation support the collection and use of necessary personal and personal health information while recognizing the need to have proper regard for the privacy and confidentiality of that personal information.

There is much debate and discussion around how privacy comes into play with COVID-19 data, and a need to achieve a balance between what information must be shared and what information must be protected in accordance with the requirements of applicable legislation. During a public health crisis, such as the COVID-19 outbreak, privacy laws still apply, but they are not a barrier to appropriate information sharing. Disclosure must be supportable in accordance with applicable legislation, for example

the release of non-identifying information (such as the numbers of affected individuals, demographic data, statistics based on geographic locations etc.) as necessary for public health purposes. When an Order in Council does not deal with an issue of disclosure, Niagara Region is required to follow its standard practices and procedures.

In addition to being a legal obligation to our residents, it is also an organizational asset that enables the critical work of Public Health. Contact tracing by Public Health requires collection of very personal details of individual's lives to understand their whereabouts and with whom they might have had contact. Residents will be most forthcoming with such personal details when they have a high degree of confidence that these details will be protected. The organization's reputation for protecting privacy is a major contributor to the confidence residents have to be forthcoming.

Privacy is not a barrier to transparency. Transparency of process and procedure, such as why an organization like Niagara Region is collecting personal information, or what it plans to do with the information it collects, are key to the protection of individual privacy. Neither the collection of information, nor the decision to disclose it should be contemplated without appropriate due diligence and review.

NRPH, and any personal health information it collects, is subject to both the *Personal Health Information Protection Act* (PHIPA) and the *Municipal Freedom of Information and Protection of Privacy Act* (MFIPPA).

PHIPA applies to Health Information Custodians, which is a term that includes medical doctors operating a practice, hospitals, and medical officers of health who collect Personal Health Information. PHIPA requires custodians like the Medical Officer of Health to protect personal health information from inappropriate use or disclosure. Personal Health Information is any information collected by NRPH, or another custodian like Long-Term Care, that can identify an individual and is about their health. Examples include a diagnosis, treatment, health history, or a health card number. PHIPA also requires that custodians provide individuals with access to their own personal health information when they request it. Personal Health Information belongs to the individual, not the custodian.

MFIPPA is a more general privacy law that applies to government institutions. It requires Niagara Region to protect personal information. Personal information is also information that can identify an individual but is not specific to health. It includes an individual's name, address, phone number, email address, or social insurance number. MFIPPA additionally allows individuals to request records and information from a

government institution, including the right for an individual to request access to their own personal information that an institution may have collected about them.

In both cases the organization, be it a health information custodian or a government institution, must only collect, use, retain, disclose, or dispose of the information it collects in accordance with its legal authorization to do so, and within a defined purpose. When NRPH discloses someone's personal health information, it must either have the consent of the individual to share that information, or the legal authority to share it without consent, in accordance with the defined purpose authorizing its collection. Any disclosure of information without consent or authority, which allows someone to identify an individual would be a breach or contravention of the law. The person or organization making the disclosure may be fined and open to civil action for breach of privacy.

These are serious issues that require contemplation and review before decisions around disclosure can be made. If information is to be made publicly available, it must first be aggregated, or de-identified in a way that makes it impossible to identify an individual; aggregation requires a minimum number of data units to be present to enable sufficient anonymity. Aggregation and de-identification are currently practiced with the statistical data being made available on the NRPH or Niagara Health's websites. This is the only way to balance the legal requirement to protect individual privacy with the right for individuals to access government information. Following the Canadian Standards Association's ten privacy principles, NRPH must rely on consent, must limit disclosures and must implement safeguards to protect sensitive information about Niagara's residents.

COVID-19 data is collected, used and disclosed by public health to support its three principle lines of response: case, contact, and outbreak management; Supporting health care and social services sectors; and public messaging. NRPH obtains consent from every person who interacts with the Region to collect their personal health information for the purpose of providing them with this care. NRPH uses the data for surveillance, providing aggregated data to Niagara Region's website and the Province, focusing on accuracy and safeguarding the information. The collection of an individual's personal health information is done so to provide them with individual health care services, as well as to assist public health in stopping the spread of COVID-19. Decisions respecting disclosure of this information are made in accordance with the directives issued by the Province of Ontario, and if the Medical Officer of Health believes on reasonable grounds that the disclosure is necessary for the purpose of eliminating or reducing a significant risk of serious bodily harm to a person or group of persons.

Niagara Region's Access and Privacy Office has received 81 complaint calls respecting the collection and disclosure of personal health information in response to COVID-19. Of those, 38 were individuals calling with concerns respecting the disclosure of their own personal information as a result of providing testing data to Niagara Region Public Health. A main concern of these individuals is being harassed by members of their communities or places of work if their test result, or details about them were to become public.

All 81 complainants were provided information respecting current policy and legislation, and given an opportunity to escalate their concerns within the Clerk's Office, or directly to the Information and Privacy Commissioner/Ontario. No formal complaints through the Commissioner's Office have been received to date.

The role of the Access and Privacy Office, which reports to the Regional Clerk, is to provide consultative services within Niagara Region related to issues of information access and the protection of privacy. Other responsibilities and services include:

- Performing Privacy Impact Assessments on enhanced and new services introduced to Niagara Region;
- Responsible for Privacy Breach Management, coordinating with programs and communications with the Information and Privacy Commissioner/Ontario;
- Facilitate and consult on health records requests;
- Coordinate and respond to formal freedom of information requests;
- Assist with program audits and evaluations, providing recommendations and risk mitigations;
- Advising departments on appropriate safeguards when publicly disclosing data or other personal or personal health information; and
- Other various tasks supporting Niagara Region staff in accordance with legislation.

If there are questions regarding our Privacy policies please contact the Access and Privacy Office, extension 3779 for more information.

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Ann-Marie Norio		
Regional Clerk		

Respectfully submitted and signed by