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AUTHORIZATION FOR INDIRECT COLLECTION OF PERSONAL INFORMATION

MINISTRY OF HEALTH

Michael McEvoy, Information and Privacy Commissioner

October 31, 2018

SUMMARY

The Ministry of Health requested authorization from the Information and Privacy Commissioner to indirectly collect personal information from health care providers, assessors, and consultants for the purposes of monitoring and overseeing the provision of medical assistance in dying (MAID) in British Columbia.

Under section 42(1)(i) of the *Freedom of Information and Protection of Privacy Act* (FIPPA), the Commissioner authorizes the Ministry of Health to indirectly collect personal information about individuals seeking or receiving MAID, and about witnesses to their written requests, from medical practitioners, nurse practitioners, and pharmacists.

This indirect collection is in accordance with the Deputy Minister of Health's obligations as a designated recipient under the federal regulations made by the federal Minister of Health pursuant to s. 241.2(3) of the *Criminal Code*. In addition, the Ministry of Health is authorized to indirectly collect personal information for the province to oversee the provision of MAID, on the conditions set out below.

This authorization rescinds and replaces the March 28, 2018 authorization for indirect collection in relation to MAID.

BACKGROUND

By letter dated October 5, 2018, the Ministry of Health requested authorization, under s. 42(1)(i) of FIPPA, to indirectly collect personal information from medical practitioners, nurse practitioners, pharmacists (collectively, “Health Care Providers”), for the purposes of monitoring and overseeing the provision of MAID to British Columbians. The Health Care Providers involved in MAID include: medical or nurse practitioners (practitioners) who receive and transfer a patient’s written request for MAID; practitioners who assess patient eligibility for MAID; practitioners who assess eligibility and provide MAID; pharmacists who dispense a substance for the purpose of MAID; and consultant practitioners who perform a patient capability assessment (if required).

On June 17, 2016, *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)*¹ received Royal Assent, amending the *Criminal Code* to permit Health Care Providers to provide MAID.

Section 241.2(3) of the *Criminal Code* requires medical practitioners and nurse practitioners who receive requests for MAID, and pharmacists who dispense substances in connection with MAID, to collect and disclose information to monitor the delivery of services in relation to MAID.

The federal Minister of Health made regulations that she considers necessary for the collection of information relating to requests for, and the provision of, MAID. She deposited the Monitoring of Medical Assistance in Dying Regulations (Federal Regulations) on August 9, 2018. The Federal Regulations come into force on November 1, 2018. The regulations define the person who collects this information as a “designated recipient”. The Deputy Minister of Health is the designated recipient for BC.

The Ministry of Health provided me with the forms required for the federal monitoring program. These forms require Health Care Providers to disclose the following information about individuals to whom they provide services in relation to MAID:

- date of birth;
- health insurance number;
- province or territory of issue of health insurance;
- postal code of the health insurance number;
- sex of the person;
- whether the request was received indirectly or directly from the patient;
- date the practitioner received the written request;
- date of referral or transfer of care of patient’s request;
- reason for transferring the patient’s request;

¹ An Act to amend the Criminal Code and to make related amendments to other acts (medical assistance in dying,” *House of Commons*, <http://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royal-assent>.

- whether the practitioner completed an eligibility assessment prior to transferring the patient and whether the practitioner felt they were eligible;
- details about the status of the person's state of decline, illness, disease or disability;
- nature of the patient's suffering;
- whether the person was eligible for health services funded by a government in Canada;
- whether the person was at least 18 years of age;
- whether the individual was capable of making this health care decision;
- confirmation that the request for MAID was voluntary and with informed consent;
- whether the individual was informed that they could withdraw their consent;
- whether the person met all of the criteria for MAID;
- date the substance being administered was administered by the physician or nurse practitioner;
- setting where the substance being administered was delivered to the person;
- whether the person withdrew the request, reasons if known;
- whether the patient died of a cause other than MAID;
- if the patient died of a cause other than MAID, whether the practitioner completed the death certificate;
- whether the physician or nurse practitioner had a therapeutic relationship with the patient prior to the MAID request;
- whether the relevant health practitioner consulted with other professionals and if so what type of practitioner they were;
- whether the person received palliative care and disability support services;
- supplementary information to clarify practitioner or pharmacist's responses;
- patient's initials confirming they meet the eligibility criteria and safeguards;
- practitioner's initials confirming eligibility criteria and safeguards met;
- another practitioner's written assessment confirming the patient's eligibility;
- confirmation that the two practitioners were independent for the purpose of the patient's eligibility assessment;
- assurance of 10 clear days between the request and MAID, and details if less than 10 days;
- assurance that the individual was provided the opportunity to withdraw and the practitioner ensured the patient gave express consent prior to receiving MAID;
- whether the patient had difficulty communicating and measures taken by the practitioner to address this;
- whether the pharmacist was informed that the substance was being administered for MAID;
- date of dispensing of drugs by the pharmacist;
- location where the substance being administered was dispensed; and
- practitioner's name, licence number, work email and mailing address.

In addition to the requirements of the *Criminal Code* and Federal Regulations, BC has implemented additional safeguards. They include:

- that a regulated health professional witness eligibility assessments conducted over telemedicine;
- one or both doctors or nurse practitioners involved in a MAID application may request a capability assessment if they are concerned about a patient's capability for providing informed consent;
- a pharmacist must dispense the drugs directly to the prescribing doctor or nurse practitioner and the prescribing doctor or nurse practitioner must return any unused drugs to the pharmacy; and
- the doctor or nurse practitioner must be present with the patient during administration or self-administration of MAID. They must remain with the patient until they confirm the death of the patient. Doctors or nurse practitioners may not delegate this responsibility to another person or professional.

The Ministry of Health also plans to implement additional oversight of MAID beyond what the federal Minister of Health requires. This oversight program will review all documentation following a medically assisted death to ensure compliance with s.241.2(1-3) of the *Criminal Code* and BC's additional safeguards for MAID, and will monitor documentation submitted for non-completed cases of MAID (related to patient ineligibility, withdrawal of request, or death from another cause). The Ministry of Health will follow-up with relevant practitioners regarding missing or incomplete information. When necessary, the Ministry of Health will refer cases to the appropriate professional regulatory college or law enforcement agency for investigation. The Ministry of Health will also track trends and patterns of compliance.

To accomplish this additional oversight, the Ministry of Health requires Health Care Providers to disclose the following information:

- patient's name;
- patient's sex (other);
- patient's home address, including postal code;
- patient's phone number;
- patient's location at the time of request;
- patient's primary health care provider's name and phone number;
- patient's preferred contact name, relationship, and phone number;
- patient's confirmation that they meet the eligibility and safeguards;
- patient's confirmation that they are over 18 years of age and making a voluntary request;
- patient's confirmation that they have been informed of diagnosis, prognosis, treatment options, and belief that their medical condition is grievous and irremediable, and suffering intolerable;

- patient's confirmation that treatments, including palliative care, have been explained to them;
- patient's consent to be assessed for eligibility and capability;
- confirmation the patient understands that information will be shared with health professionals and as required by law;
- confirmation the patient had the opportunity to ask questions and request information, and may continue to do so;
- confirmation that the patient's expectation is death when the prescribed medication is administered;
- confirmation that the patient understands they have the right to change their mind at any time;
- patient's signature and date;
- witnesses initials confirming safeguards met;
- confirmation that the witness knows the individual or has provided proof of identity;
- patient or proxy signed the patient's request in the presence of the witness;
- confirmation the witness is not a beneficiary under the patient's will or recipient in any other way of material benefit from the patient's death;
- the witness is not the owner or operator of the facility where the patient receives treatment or resides;
- the witness is not directly involved in providing health care services to the patient;
- the witness does not directly provide personal care to the patient;
- details of where a practitioner transfers a patient's request, such as to a MAID Care Coordination Service;
- practitioner's signature, date and time signed for the referral of a patient's request;
- consultant practitioner's signature, date and time signed confirming whether patient has the capability to provide informed consent for MAID;
- practitioner's signature, date and time signed confirming an individual's eligibility for MAID;
- practitioner's indication of patient's choice for practitioner or self-administered MAID;
- planned date and location for MAID;
- planned number of days from initial request and, if fewer than 10, the reason why;
- practitioner's indication of how express consent was provided and steps taken if not by signature;
- practitioner's confirmation that the patient is fully informed of the diagnosis and prognosis, of the potential risks of medication and outcome, and of the recommendation to seek advice on life insurance implications;
- whether patient is fully known to the practitioner or provided proof of identity and consent to assessment;

- confirmation the practitioner will not benefit from the patient's will or receive financial or material benefit from the patient's death;
- practitioner's initials that they have planned for potential issues, such as failure of IV access;
- practitioner and pharmacist's indication that they have undergone planning, including the return of drugs;
- practitioner's initials that the prescribed medication is for MAID;
- whether the assessment was done in person or via telemedicine;
- date and location of assessment;
- patient's medical information, such as allergies, for MAID prescription purpose;
- name of second assessor confirming patient's eligibility;
- practitioner's indication of all IV or oral drugs prescribed for the patient and administered or self-administered;
- practitioner's date and time signed for the prescribed IV or oral drugs;
- pharmacist's initials confirming drugs are for MAID;
- planned prescription/substance release date and time;
- planned date and time for return of unused drugs;
- pharmacist's indication that the prescriber was instructed in how to complete the medication administration record;
- pharmacist's confirmation of prescriber's photo ID, if applicable;
- if the patient had to be transferred to a location for MAID, whether that transfer was due to an originating facility's policy regarding MAID provision;
- date and time of return for unused drugs;
- list of returned drugs (name, strength, quantity, and whether consistent with what the prescriber has indicated on the medication administration record);
- pharmacist's signature, date, and time for dispensing and receipt of returned drugs;
- professional interpreter's name, ID, and date of service, if applicable;
- proxy's name, phone number, relationship to patient, signature and date signed, address, and postal code, if applicable;
- witness' name, relationship to patient, phone number, address, and postal code;
- witness' initials indicating safeguards met;
- witness' signature and date signed; and
- telemedicine witness' name, profession, and college ID.

DISCUSSION

Section 27 of FIPPA requires that a public body collect personal information directly from the individual the information is about, with specific exceptions. The basis of this requirement is the privacy principle that individuals should have control of their personal information and that the collection of personal information should be transparent so that individuals can exercise their privacy rights. One of the exceptions to the requirement of

direct collection is authorization from the Commissioner for the public body to collect personal information from sources other than the individual the information is about under s. 42(1)(i) of FIPPA.

In previous decisions where the exercise of the Commissioner's discretion under s. 42(1)(i) was at issue, the following questions have been considered:

1. Has a clear and sufficiently compelling public interest or objective been identified that cannot reasonably be accomplished through direct collection of personal information?
2. Is the requested departure from FIPPA's rule of direct collection clearly justified when judged against the nature of the personal information to be collected and the purpose for which (and to whom) it is to be disclosed or used?

I have considered these same questions in relation to this request.

Compelling Public interest

The Ministry of Health submits that its indirect collection of the personal information about a person who has requested MAID is for the purpose of health care administration and oversight of the provision of MAID in the province. By collecting this personal information as a designated recipient under the Federal Regulations, the Deputy Minister of Health is streamlining the collection of this personal information from Health Care Providers and avoiding duplication of that collection by Health Canada.

I accept the Ministry of Health's submission that the provision of MAID warrants care and scrutiny, evaluation, monitoring for compliance, and accountability to the public by both the provincial and federal governments.

The regulatory impact analysis statement of the Federal Regulations states that:

Medical assistance in dying in Canada is permitted through exceptions to criminal laws which prohibit intentionally ending or helping to end another person's life. A robust monitoring regime reflects the significance and gravity of permitting practitioners to intentionally end life.²

Monitoring the provision of MAID is a clear and sufficiently compelling public interest that the Ministry of Health and federal government cannot reasonably accomplish through direct collection of personal information.

The Ministry of Health shares the interest of Health Canada in wanting to ensure that Health Care Providers deliver MAID in an appropriate manner and in accordance with eligibility criteria and safeguards in the federal regulatory framework. It is important that the Ministry of Health receive information about the provision of these services in a timely manner so that, if there are concerns, the Ministry of Health may take remedial

² <http://www.gazette.gc.ca/rp-pr/p2/2018/2018-08-08/html/sor-dors166-eng.html>.

action such as an investigation, communication with a professional regulatory body or the police, or issuance of policy or guidelines. Given its responsibility for the delivery of health services in BC, the Ministry of Health has a legitimate and significant role to play in the administration of the federal and provincial MAID schemes.

The alternative to oversight is a complaint-driven process. The Ministry of Health asserts that a complaint process is not appropriate nor in the public interest when it comes to MAID. As BC provides accessibility to MAID eligibility assessment in ways beyond the Federal Legislation, such as telemedicine, as well as providing additional safeguards concerning patient capability assessment, the presence of the practitioner with the patient during MAID, and the protective custody of dispensed substances for MAID, it is reasonable that the Ministry of Health will need additional data for oversight of those services.

I agree that the Ministry of Health requires access to all completed forms, rather than to select data elements, in order to closely monitor the demand for, and the delivery of, MAID within the publicly funded health care system. The collection of information for the purposes of legal compliance, health care administration and planning, accessibility, and funding provide a compelling public interest for the Ministry to indirectly collect this personal information related to MAID.

Indirect collection

Section 27(1)(a)(iii) of FIPPA authorizes indirect collection when it is authorized by an enactment. The *Interpretation Act* defines an “enactment” as an Act of the Legislature or a regulation. “Legislature” means the BC Legislature, not the Parliament of Canada. Therefore, while the Federal Regulations authorize the indirect collection of the personal information at issue, FIPPA does not recognize the Federal Regulations as an enactment, and authority for indirect collection.

As a result, the Deputy Minister of Health requires the authorization of the Commissioner pursuant to ss. 27(1)(a)(ii) and 42(1)(i) of FIPPA to indirectly collect this information as a designated recipient under the Federal Regulations.

The Ministry of Health further submits that it is responsible for operating provincial health programs. MAID is a unique health program that results in the patient’s death. When considered with the federally legislated requirements, as well as the mandate of the Ministry to monitor and operate health programs for British Columbians, it argues that ensuring compliance with the federal and provincial regulations governing MAID justifies the indirect collection of personal information.

The personal information sought by the Deputy Minister of Health as the designated recipient is highly sensitive. It includes data about individuals who have sought and/or received MAID from Health Care Providers, as well as personal information about individuals who have served as witnesses, proxies, and interpreters to requests. This indirect collection will occur without notice to the individuals the information is about.

The statement of understanding between the Deputy Minister of Health and Health Canada requires the disclosure of the data to Health Canada, which is subject to the federal *Privacy Act*. The Ministry of Health will use the information for monitoring and overseeing the delivery of MAID and for administrative and planning purposes. The Ministry of Health may only use and disclose the personal information as permitted by FIPPA. Further, the Ministry of Health is required by FIPPA to make reasonable security arrangements to protect the data.

Given that the Federal Regulations require the collection of certain personal information, I accept the justification for indirect collection of personal information about individuals who have sought and/or received MAID, the reasons they have chosen to do so, and the means of providing MAID, as needed to determine whether MAID is provided in compliance with the law. The timely collection of that personal information is in the interests of British Columbians, and will allow the Ministry of Health to fulfill its responsibilities to administer the health care system.

In addition, the province has established additional safeguards related to the provision of MAID services. These services require the constant oversight of medical practitioners. If each step required practitioners and patients to submit their own paperwork to the Ministry of Health, oversight would slow from the unnecessary duplication of paperwork. Further, forms would likely be incomplete, with no way to ask the patient to re-fill a form. I agree that indirect collection of this personal information is the only feasible means for collection by the Ministry of Health. I also agree that this information is necessary to conduct its own assessment of whether MAID is being delivered in compliance with the law and whether improvements or remedial actions are required to ensure every patient is treated appropriately.

AUTHORIZATION

For the reasons noted above, under s. 42(1)(i) of FIPPA, I authorize the Ministry of Health to indirectly collect personal information from Health Care Providers about individuals seeking or receiving MAID, about witnesses to their requests, confirmation of the regulatory checks related to patient consent, services provided during patient consultation, and the dispensing of prescription substances. The Deputy Minister of Health may use and disclose this information in accordance with its obligations as a designated recipient under the Federal Regulations and for operating its MAID oversight program, subject to the following conditions:

1. The Ministry of Health must notify me of any changes to the Federal Regulations or provincial standards that would require the Ministry of Health to indirectly collect any personal information beyond what I have identified in this authorization.

2. This authorization will expire on the sooner of the coming into effect of an enactment, which expressly authorizes the Minister of Health to indirectly collect the information for the purposes of monitoring and overseeing the provision of MAID or November 1, 2020.

October 31, 2018

A handwritten signature in blue ink, appearing to read "M. McEvoy", with a large circular flourish at the end.

Michael McEvoy
Information and Privacy Commissioner
for British Columbia