

**NORTHWEST TERRITORIES
INFORMATION AND PRIVACY COMMISSIONER**
Review Report 16-HIA01

File: 15-165-6
June 21, 2016
Citation: 2016 NTIPC HIA 01

BACKGROUND

On October 1st, 2015, the *Health Information Act* came into force. Section 2 of the Act notes that the purpose of the legislation is to

govern the collection, use, disclosure and protection of personal health information in a manner that recognizes both the right of individuals to access and protect their personal health information and the need of health information custodians to collect, use and disclose personal health information to support, manage and provide health care.

On October 1st, I received the first complaint filed under the Act. The Complainant has had ongoing struggles with the health system and, in particular, Yellowknife Health and Social Services Authority (YHSSA), over his ability to control who has access to his health information. His complaint was, perhaps, somewhat premature in that he had not had any contact with the health system since the coming into effect of the Act, but it is clear from the correspondence exchanged during the course of this investigation that his frustrations have continued and that the approach taken by YHSSA in addressing the issues has not changed from prior to the coming into force of the Act. I therefore felt that it was important to complete this review to address whether YKHSSA's policies and procedures are in keeping with the requirements imposed by the new legislation. My

recommendations will, however, be prospective with a view to moving forward, rather than retrospective.

The Complaint

The Complainant sought a review of the privacy policies and procedures of YHSSA, with specific focus on the following:

- a) the lack of any means for patients to control the sharing, use of and access to their personal health information as dictated by the new legislation;
- b) his perception that he is unable to obtain needed medical assistance without being subjected to a lengthy explanation about the dangers of limiting access to his personal health information every time he sees a different physician and the unwillingness or inability of YHSSA to provide a patient with an accessible primary physician so as to allow access to health services without having to endure the same "lecture" every time he has an appointment;
- c) his perception that while the Health Information Act provides patients with privacy rights, there is no way to avail oneself of those rights without giving up the right to actually receive health services.

Many of the concerns raised by the Complainant stem from the fact that there is only one service provider for primary health care in Yellowknife and, indeed, in the Northwest Territories. In Yellowknife, YKHSSA has a virtual monopoly on the provision of primary health care and the patient has no choice about who their primary health care physician might be or if they can ever actually have access to that physician as opposed to another physician on the "team". Furthermore, all of the staff of any given health facility have access to the medical health records of all

patients who attend the facility, subject only to the limitations set by the roles based access to the electronic records.

It should be noted that the Complainant has had a long history of concerns about the collection, use and disclosure of his personal health information by various employees of YHSSA. As a result, he provided YHSSA with a “personal directive” with respect to the sharing of his personal health information within YHSSA in the summer of 2014. That directive provided as follows:

- a) No more sharing. No "integrated service delivery mode". No team based approach. I am in charge of my medical care and I decide when, how and to whom and if information needs to be shared between any service or care providers;
- b) No sharing between YHSSA Social, Adult or Mental Health Services amongst themselves;
- c) No sharing from YHSSA Social, Adult and Mental Health Services with YHSSA Primary Care;
- d) No sharing between YHSSA primary care to YHSSA Social, Adult and Mental Health Services;
- e) No sharing between service areas of Stanton and any part of YHSSA with the exception of testing and emergency services;
- f) YHSSA and DHSS administrators and executives are not to have any access to my personal information or patient records;
- g) No use is to be made of my personal information or patient records except in the provision of care as requested by me (research, statistical gathering);
- h) No further sharing of any personal, medical or mental health records to an employer without my permission;

- i) No sharing of my personal information or patient records to random members of the public;
- j) Should I feel that sharing is warranted I am happy to provide authorization for limited, time based sharing of information - with my signature. Please note that I will not be providing any verbal authorizations, ever.
- k) Finally Dr [A.B], Dr.[C.D.] and Dr. [E.F.] are not to have any access to my personal information or patient records either verbally or in written form, up to and including appointment bookings with any other care provider. I am requesting that I become invisible to them and that my medical and patient needs are not discussed with them.

As recently as the month before the complaint was made, this privacy directive appears to have been breached by a medical practitioner who the Complainant had seen for the purposes of having blood testing done. The Complainant had met with the medical practitioner to have the results of his blood tests explained. During that appointment, it was suggested that the Complainant have his blood tested again in approximately 4 weeks. It was understood that the medical practitioner would be away for a period of time and the next appointment was, therefore, purposely set for a date after her intended return. Notwithstanding the existing directive and the deliberate choice of the next appointment, the medical practitioner sent the Complainant an email indicating that “in accordance with my professional obligations, I will be signing out my practice to Dr. [G.H.]” while she was away.

YHSSA’s Submissions

I asked YHSSA to address the Complainant’s concerns in light of the new *Health Information Act*. In specific response to the three concerns raised by the Complainant, the responses were as follows:

1. With respect to the complaint that there was no means for patients to control the sharing, use of and access to their personal health information as dictated by the new legislation, YHSSA provided the following:

The Yellowknife Health and Social Services Authority (YHSSA) has made many attempts to work with [the Complainant] in order to place reasonable limits on who can access his personal health records. YHSSA remains open and willing to work with [the Complainant] to address his concerns outlined in his privacy directive; keeping in mind a solution must balance his right to limit the collection, use and sharing of his personal health information with the needs of YHSSA health service providers to collect, use and share client information in order to provide best care.

On several occasions, YHSSA has provided [the Complainant] with specific options to address his privacy concerns. Please refer to the attached letter I sent to [the Complainant] on October 17, 2014. The "Conclusion and Options Going Forward" section outlines potential options for [the Complainant]'s consideration. To date, we have not received a response from [the Complainant] in relation to the proposed options.

2. With respect to the complaint that he is unable to obtain needed medical assistance without being subjected to a lengthy explanation about the dangers of limiting access to his personal health information time he sees a different physician, YKHSSA provided the following response:

On several occasions, I have facilitated medical appointments with YHSSA practitioners on behalf of [the Complainant]. However, [the

Complainant's] privacy directive raises a number of safety concerns that would limit the ability of a practitioner to provide him with safe and appropriate care. As a health information custodian under the Health Information Act (HIA), YHSSA and its agents (practitioners) have a duty to inform [the Complainant] of the implications associated with implementing his privacy directive which is in accordance with section 23 (3)(a) of the HIA.

3. And with respect to the Complainant's allegation that there is no way to avail oneself of the privacy rights granted to patients under the new *Health Information Act* without giving up the right to actually receive health services, YKHSSA provided the following:

Under the HIA, [the Complainant] has a right to know who has accessed his health information. Regular audits of the EMR and HealthNet Viewer are carried out to ensure the proper protection of patient privacy. [The Complainant] can request an audit to confirm who has accessed his health information. Additional audits can be carried out at [the Complainant's] request. This can be combined with express instructions made to YHSSA, in this case, that particular providers are not to view his health information.

Additionally, the Department of Health and Social Services' Health Privacy Unit is developing guidelines for masking best practices. The Department is working with its vendor to have functional masking capability in the EMR so that certain providers could be blocked from viewing part or all of a record. The current version of the EMR does not yet have that capability. Health service professionals are also governed by their professional codes of ethics and standards of

practice, and receive guidance from their professional associations, all of which will influence how they could comply with express instructions and how they can apply masking requests.

Based on this response and further input from the Complainant, I asked the public body to address, specifically, the sections of the *Health Information Act* which they were relying on to justify their approach and, in particular, how they were interpreting section 22(2)(iii) of the Act. I also asked them to provide me with copies of any “established standards of professional/institutional practice” from the governing bodies of the various medical care professionals which would, in their opinion, allow them to disregard a patient’s directive with respect to the collection, use and disclosure of their personal health information, as well as any specific new policies and procedures developed to deal with the types of concerns/issues raised by the Complainant. It should be noted that this request was made in January, some three and a half months after the coming into effect of the *Health Information Act*. I asked, in particular, whether any practices had been developed to accommodate individuals like the Complainant who were not prepared to allow YHSSA to rely on “implied consent” to the use and disclosure of his personal health information.

In response, the public body provided some insight into their interpretation of a number of sections of the Act. They referred to section 22(2) which they say addresses the ability of patients to place conditions on the sharing of their personal health information. They acknowledge that the section allows for such patient controls, but note that “such conditions do not have a retroactive effect” and that such conditions are not effective in a number of circumstances including where the condition purports to prohibit or restrict the recording of any information by a health information custodian that is required by law or by established standards of professional or institutional practices. As an example of the latter, they note that

“most standards require that a health provider keep documentation of each visit with a client”.

They also refer to section 22(3) which provides that when a custodian is asked by a patient to limit access to their personal health information, the custodian must:

- (a) inform the individual of the implications of the limitation;
- (b) take reasonable steps to comply with the limitation;
- (c) attach the limitation to or record the limitation on the applicable record; and
- (d) take reasonable steps to give notice of the limitation to other persons and organizations to which the custodian discloses the information.

Finally, they argue, that section 23 of the Act addresses the specific situation where a client asks their practitioner not to disclose information that the practitioner considers to be relevant to the provision of care by another practitioner. They point to the provisions of the GNWT Health Information Act Guide, which uses an example of a patient who asks that their practitioner not to tell their orthopedic surgeon about a history of addictions to prescription drugs. The example says that the practitioner in such circumstances is required to advise the patient of the consequences of such a request - “i.e the client may not receive safe care and the orthopedic surgeon might refuse to treat him”. They note that if a health information custodian only discloses a limited amount of personal health information about an individual to a health service provider for the purposes of providing or assisting in the provision of a health service to the individual because of the existence of a condition limiting use or disclosure of the patient’s personal health information, and the disclosing custodian considers the undisclosed information to be reasonably necessary in respect of the provision of or assistance

in providing the health service, the disclosing custodian must give notice to the health service provider to which it discloses the information.

In response to my request for copies of any new policies, procedures or guidelines developed to deal with patients who request conditions on the use and disclosure of their personal health information, the public body merely referred to the requirements set out in the *Health Information Act*. They note that Chapter 3 of the Health Information Act Guide provides guidance around how to address consent conditions but “due to the expected unique nature of a client’s consent conditions, YHSSA is not planning to develop a specific policy around this.”

YKHSSA notes that

there may be times where a health service provider or health and social services organization will not have the ability to comply with certain consent conditions. For example, a client may specifically instruct that personal health information be "masked" or hidden from view in an electronic health record (EMR) information system. At the present time, YHSSA’s EMR system does not have the technical capacity to mask information; therefore, masking is currently outside YHSSA’s institutional practice. Additionally, if masking information is not considered within a health service provider’s professional standards, the health service provider is not required to meet the condition.

The Complainant’s Response

The Complainant, in his response, first referred me to the electronic brochure on the Department of Health’s web site entitled: Health Privacy - Protecting your Health Information located at the following address:

<http://www.hss.gov.nt.ca/health/slides/health-privacy-protecting-your-health-information>

and, in particular the statement in that brochure which states that “Individuals can set limits and conditions on how their information may be collected, used or shared”.

As noted, the Complainant has a fairly long history of concerns about the way in which his personal health information has been used and disclosed by YKHSSA. He is less than confident in the ability of the organization to limit the use of his information. He notes that he is unable to connect with one care provider for consistent care, which means that he must see whoever is available on a particular day and that every time he sees another practitioner, he must “debate his rights” and, in his experience, his instructions are, in any event, ignored. He notes that in one instance, he had to listen to a doctor’s “lecture” for 30 minutes and endure ongoing “threats” of “no health care in the future” and “no doctor would agree to provide me with health care if I insisted on privacy” for the duration of the appointment. He equates this to being coerced to go along with the free sharing of his personal health information. He notes that lawdictionary.org defines coercion as:

Compulsion; force; duress. It may be either actual, (direct or positive.) where physical force is put upon a man to compel him to do an act against his will, or implied, (legal or constructive.) where the relation of the parties is such that one is under subjection to the other and is thereby constrained to do what his free will would refuse.

He goes on to say:

Given the power imbalance inherent in a medical appointment, especially with a different care provider each time, I feel that what YHSSA - a monopoly - is doing to me is coercion in order to get me to abandon my privacy rights.

In his opinion:

The only rights it (the *Health Information Act*) appears to confer is to organizations like YHSSA who for all intents and purposes can do whatever.... they want with PHI as long as they invoke terms such as safety, circle of care or professional standards.

The Complainant points out that YHSSA has relied on “professional and organizational” standards to allow them to disregard the patient’s rights as conferred by the Act and would appear to be able to use this “out” with impunity to ignore the protections given to individuals to control the use and disclosure of their personal health information. He notes as well that:

DHSS [the Department of Health and Social Services] has published an HIA [Health Information Act] guide that uses 4 pages to tell the public how they can share our information but only 3 sentences to cover the right of patients to set limits, and no examples that show how a patient can exercise those rights. That's a very strong message.

He says that his experience in with YHSSA has left him with the following impressions about the system of providing health services in Yellowknife:

- express written instructions by a patient can be ignored;

- professional obligations trump patient rights in the HIA;
- there is no publicly available information detailing professional or institutional standards/obligations;
- the HIA was passed without any knowledge of what those standards and obligations consist of, or how they impact the HIA and patient rights.
- patients are not allowed to control the sharing, use or access of their PHI, or to assume any risk to obtain privacy rights unless an employee of YHSSA allows;
- the public has fewer rights under the new act, and HA's have more rights than patients.

The Complainant notes that the public is now being “shoe-horned” into a model of medical health delivery whereby a person is assigned to a group of 5-7 doctors with the hope that a person may be able to see one of that grouping when seeking health care, and that patient information is shared between that group freely. He notes that this does not allow the patient to establish a trusted therapeutic relationship with his family physician and notes that if the average person sees a doctor 1-2 times a year, given the rate of employee turnover at the clinics run by YHSSA, a person could go three years or more without seeing the same provider twice. Additionally, he notes, the public is not allowed to restrict the sharing of their PHI within that group, or have a say in its membership and that there is no effort made to ensure that patients are aware of their rights or have choices with respect to the sharing of their personal health information.

He argues that YHSSA keeps relying on the word “safety” in denying individuals the right to control over their personal health information, effectively saying that the public is not allowed to assume responsibility for their own bodies and health.

Should he not, he queries, have the right to assume any risks that come with his privacy directive? To suggest otherwise, he states is “arrogant” and “paternalistic”.

The Law

As noted, the *Health Information Act* is relatively new legislation. This is the first review of the Act by the Office of the Information and Privacy Commissioner. It is important, therefore, that a thorough review of the law is done, at least insofar as it relates to the issues raised in this complaint.

We start with a consideration of the purposes of the Act as set out in Section 2:

The purpose of this Act is to govern the collection, use, disclosure and protection of personal health information **in a manner that recognizes both the right of individuals to access and protect their personal health information and the need of health information custodians to collect, use and disclose personal health information** to support, manage and provide health care.

(Emphasis added)

We begin, then, with the need to balance the patient’s right to control who can use and disclose his/her personal health information while still meeting the needs of the health provider to deliver health services. Neither of these purposes trumps the other. They must be balanced.

Also as a preliminary matter, I note that all health information custodians, as defined under the *Health Information Act* are required by section 8 to “establish or adopt standards, policies and procedures to implement the requirements” of the Act and the Regulations. It is therefore of some considerable concern that YHSSA

has deliberately chosen not to create any policies or procedures around the two primary goals of the Act - to address how individuals can exercise their rights to control the use and disclosure of their personal health information and still receive good medical care.

Another important part of the Act which appears to have been overlooked or ignored by YHSSA is Part 3 which deals with consent and substitute decision makers. For the purposes of this review, it is the consent provisions which are important. This is a fairly complicated part of the Act and it is therefore important to review it carefully:

Section 17 provides that medical practitioners can rely on implied consent to the collection, use, or disclosure of personal health information if:

- (a) it is reasonable in the circumstances for the health information custodian that collects, uses or discloses the information to infer that the individual consents to the collection, use or disclosure; and
- (b) the consent is knowledgeable.

Section 14 provides guidance for when consent is knowledgeable:

For the purposes of sections 15, 17 and 18, a consent to the collection, use or disclosure of personal health information about an individual is knowledgeable if it is reasonable in the circumstances for the health information custodian to assume that the individual knows

- (a) the purposes of the collection, use or disclosure; and
- (b) that the individual may provide or withhold consent.

Section 15(1) provides that where consent is required for the collection, use or disclosure of personal health information, the consent must:

- (a) must be a consent of the individual;
- (b) must relate to the information;
- (c) must be knowledgeable; and
- (d) must not be obtained through deception or coercion.

Section 15(2) provides that a health information custodian may assume that an individual knows the purpose for the collection, use or disclosure of personal health information where the health information custodian has informed the individual about the purposes and:

- (a) posts or makes readily available a notice with information describing the purposes of the collection, use or disclosure, in a location where the notice is likely to come to the individual's attention; or
- (b) gives a notice to the individual describing the purposes of the collection, use or disclosure.

Section 15(2) also provides, however, that this section does not apply if it is “unreasonable in the circumstances to make the assumption”.

Section 18 allows that a health information custodian collecting personal health information from an individual for the purpose of providing or assisting in the provision of a health service to the individual may assume that the individual has provided his consent to the custodian’s

- (a) posts or makes readily available a notice with information describing the purposes of the collection, use or disclosure, in a location where the notice is likely to come to the individual's attention; or
- (b) gives a notice to the individual describing the purposes of the collection, use or disclosure.

This allowance does not apply to the **disclosure** of personal health information where the custodian collecting the information is aware that the individual has expressly withheld or withdrawn consent or has provided an express instruction that the information may not be disclosed.

One must shift through all of these provisions to focus on what is important for the purpose of this review. As I read it:

- a) consent of any kind (implied, assumed, or explicit) is not a valid consent if it is not knowledgeable;
- b) in order for consent to be knowledgeable, the custodian must inform the patient how the information will be collected, used and disclosed AND post relevant information about collection, use and disclosure in a prominent place or give notice to the individual describing the purposes of the collection, use or disclosure.
- c) the consent must not be obtained through deception or coercion
- d) the patient must know that he has the right to withhold consent

In this case, there is nothing to suggest that YHSSA took any of the steps necessary to allow them to rely on implied consent from the Complainant. There are no notices posted in the waiting areas or in the examination rooms in the YHSSA offices that advise a patient about his or her privacy rights. Nor was I able

to find any paper brochure on site. There is some information on the web site of the Department of Health and Social Services, as referred to by the Complainant, but not all patients can be expected to have gone to the web site to look at that information. I will leave the content of the Department notice to another day other than to say that it is extremely limited in information to the patient about his/her rights to control over his or her personal health information.

In these circumstances, it cannot be said that any consent of any patient (including the Complainant, to the extent that consent was implied) was “knowledgeable consent”. Nor is there any indication that patients are being advised of their right to withhold consent, which voids any consent implied or explicitly given.

Sections 22 and 23 of the Act provide that, even where consent is given (either explicitly or implied) “conditions” may be put on that consent. These conditions may be placed at the time of the consent or after consent is provided. These conditions do not have retroactive effect. Nor can such conditions be used to:

- a) limit collection, use or disclosure that is required by the *Health Information Act* or any other Act;
- b) limit collection, use or disclosure that is for the purposes of a program established under the *Pharmacy Act* to monitor prescriptions;
- c) prohibit or restrict the recording of any information by a health information custodian that is required by law or by established standards of professional or institutional practice
- d) in any other prescribed circumstances

Other than these specific exceptions, there are no limits to the conditions that a patient can put on the collection, use or disclosure of his/her personal health information. As noted by YKHSSA, when conditions are placed on the collection,

use or disclosure of personal health information, section 22(3) requires the health information custodian to:

- (a) inform the individual of the implications of the condition;
- (b) take reasonable steps to comply with the condition;
- (c) attach the condition to or record the condition on the applicable record; and
- (d) take reasonable steps to give notice of the condition to other persons and organizations to which the custodian discloses the information.

Further, also as noted by YHSSA, section 23 provides that if a health information custodian only discloses a limited amount of personal health information about an individual to a health service provider because of a condition placed by a patient on his or her consent limiting full disclosure, and the disclosing custodian considers the undisclosed information to be reasonably necessary in respect of the provision of or assistance in providing the health service, the disclosing custodian shall give notice to the health service provider to which it discloses the information that:

- (a) the disclosure is limited because of the condition; and
- (b) the custodian considers the undisclosed information to be reasonably necessary in respect of the provision of or assistance in providing the health service.

DISCUSSION

As noted, this is the first complaint received pursuant to the *Health Information Act*. This is a complicated and difficult to read piece of legislation and it will take everyone, including the Department of Health and Social Services and Health Authorities, some time to fully understand it and implement it fully. I note, as well,

that the Act does not have any retrospective effect. The Complainant's previous experiences with privacy breaches or perceived privacy breaches cannot be redressed by application of the new Act. The Act has, however, now been in effect for almost ten months and there is no indication that YHSSA has changed the way it does business in order to comply with the legislation. These recommendations, therefore, address the need for YHSSA to make changes to comply with the legislation. The *Health Information Act* clearly gives individuals the right to a significant amount of control over their personal health information and those rights must be respected even if a health authority considers the exercise of those rights to be unreasonable or conditions imposed make additional work for staff. On the other hand, I strongly recommend that the Complainant temper his demands somewhat so as to allow YHSSA to provide him with needed medical services within the confines of the requirements of the Act.

The initial complaint has three main focusses:

- a) the perceived lack of any means for patients to control the sharing, use of and access to their personal health information as dictated by the new legislation;
- b) the perception that "threats" are used to deny the patient medical health care if he chooses to avail himself of the rights provided to him through the legislation and the insistence of YHSSA, or its individual agents, on subjecting patients who attempt to exercise their rights to repeated and lengthy explanations about the dangers of limiting access at the beginning of each visit;

- c) the perception that patients are unable to effectively exercise their rights to control the use and disclosure of their personal health information without giving up the right to actually receive health services.

To address these issues, we must look at the Act, exactly what it says, and whether or not the policies and procedures in place at YKHSSA comply with the legislation.

1. Consent

Consent is at the core of the issues raised. As noted above, the Act allows health information custodians to rely largely on implied or assumed consent in many circumstances. This implied consent allows the custodian to allow those who “need to know” to use personal health information as necessary to provide medical health services to individuals. This implied consent, however, does not simply arise out of the blue when a patient arrives in the clinic and asks for medical assistance. Before a health information custodian, or its agents, can “assume implied consent”, certain steps must be taken to ensure that the patient understands how his/her information will be used and disclosed and that the consent is knowledgeable. YHSSA has not put into place any policies or procedures to ensure that they are able to legally rely on implied knowledgeable consent from any patient for the collection, use and disclosure of personal health information within their organization. It does not appear that the patient is given any information about how his/her information will be collected, used or disclosed. Nor is the patient advised, at any point, that he/she has the right to limit access to, or use or disclosure of his/her personal health information. The patient is simply not provided with any information at all about his/her rights to control how his information is collected, used and disclosed. There are no posters or brochures in the waiting rooms or in the examination rooms. The Act clearly requires health information custodians to

provide this information before they can assume implied consent. **I therefore recommend**, as a first step, that within three months, YHSSA develop informational brochures which outline the patient's rights with respect to the collection, use and disclosure of personal health information, in as many as the official languages as possible. These brochures should include, in a broad way, how personal health information will be used within the organization (e.g. diagnosis, treatment, care, billing, etc.) and how and in what circumstances that information will be disclosed to third parties. The information included in the brochure should include information about the use of electronic records and how access to records is controlled within the electronic record system (i.e. audited roles based access) and about the "team" approach to medical care and how that affects access to personal health information. The brochure **must** also clearly indicate that patients can put conditions or limits on how their personal health information is used and who has access to it. Further, the brochure must provide contact information for someone within the organization who is available to answer questions or help the patient with placing conditions on their consent. Finally, the brochure should advise patients of their right to find out who has had access to their electronic medical record and to request that an audit be done.

I recommend that this brochure be provided to every patient who seeks medical care at any facility operated by the YHSSA for at least one year and be provided to all new patients of the clinic thereafter. The brochures should also be available in clinic waiting rooms. I note that the information contained on the Department of Health and Social Services web site does not address these issues and is not sufficient for the purpose of providing patients with the necessary information to give "knowledgeable" consent.

I further **recommend** posters be developed for posting in waiting rooms and examination rooms of the all of YHSSA's clinics. These posters should alert

patients to the fact that the *Health Information Act* gives them certain rights with respect to the collection, use and disclosure of their personal health information and provide contact information for those with questions.

I also **recommend** that materials be prepared and uploaded to YHSS's web page containing the same kind of information, in more detail than is available either on the poster or in the brochures.

Until this is done, and patients have a real way of knowing that they have rights and control over their personal health information, there can be no "knowledgeable" consent, implied or otherwise.

2. Placing of Conditions

Sections 22 and 23 of the Act clearly and unequivocally allow individuals to put conditions on the collection, use and disclosure of their personal health information, subject only to a few narrow exceptions. None of those exceptions apply to the situation described by the Complainant. The exception apparently being relied on by YHSSA to limit the ability of the Complainant to place conditions on access to his records is section 22(2)(iii) which provides that no such condition can prohibit or restrict **the recording of information** by a health information custodian that is required by law or by established standards of professional or institutional practice. The Complainant's "personal directive" does not attempt to limit, in any way, the recording of his personal health information. His directive is solely about controlling who has access to his personal health information and when his personal health information can be disclosed to third parties. Section 22(2)(iii) does not apply so as to limit, in any way, the effectiveness of his personal directive.

In this case, the Complainant provided YHSSA with a personal directive dictating how his personal health information could be used and disclosed more than a year before his ability to have that control was given to him by law. This directive should have been honoured pursuant to the *Access to Information and Protection of Privacy Act*. It was not. As of October 1st, 2015, however, the *Health Information Act* clearly gives the patient the right to make such directives and to limit access to and use and disclosure of personal health information. The Act makes the Complainant's "personal directive" one that the health system must honour and work with.

I note with some concern the statement made by YHSSA that their electronic medical record (EMR) system does not have the technical capacity to mask information. They go on to say that masking is therefore "currently outside YHSSA's institutional practice" and that it is not, therefore considered "within a health service provider's professional standards" so they do not have to respect any conditions imposed by a patient to prevent certain individuals access to their personal health information.

There is nothing in the Act that says that if a health care custodian does not have the technical ability to mask records, it can ignore a personal directive or conditions placed on the use of personal health information in its possession. The Act creates rights for patients and obligations for health information custodians. If the custodian doesn't have the technical ability to comply with the rights given to patients, they must obtain the appropriate technology. As noted above, section 22(2)(iii) does not give health information custodians the right to ignore conditions set by a patient under the Act due to "professional or organizational standards" unless that condition purports to limit the recording of information required by law or practice. This exception has nothing to do with conditions which purport only to limit the access to, use or disclosure of information.

YHSSA correctly points out that when an individual places a condition on his/her consent to the collection of, access to, or use or disclosure of his/her personal health information, section 23(3) of the Act requires the health information custodian to "inform the individual of the implications of the condition". In the case at hand, the Complainant feels that he does not need the same warning every time he sees a new care provider. I agree. The health information custodian does have the obligation to inform the patient about the possible implications of conditions put on the use/disclosure of personal health information and the patient must subject himself or herself to that "lecture" as a condition of placing a condition on his file. Once done, it should be noted on the patient's file that he/she has been advised of the implications and that notice should reside alongside the conditions imposed so that health care providers can satisfy themselves that the obligation has been met. If YHSSA thinks that it is necessary, have the patient sign an acknowledgement or waiver that he/she has been informed about possible implications of the conditions placed and that he/she accepts the inherent risks associated. The information provided to the patient should **not** contain threats which suggest that the imposition of such conditions may or will likely prevent him from receiving needed medical treatment or that the patient must choose between full disclosure or not obtaining needed medical attention. I agree with the Complainant that such threats, in most cases, amount to coercion and any consent given in such circumstances would be ineffective. YHSSA has not been able to provide me with any written ethical code which suggests that a physician or any other health care provider can refuse to provide basic medical care unless full access is granted to the patient's medical records. I understand that physicians may feel uncomfortable about treating a patient without all of the relevant information in front of them. This is addressed under the Act by placing a note on the record that there may be additional information about the patient that is not reflected in the record. In such a case, if a health care advisor considers it necessary to have access to more information, it would be incumbent on the physician to speak with the patient

directly and explain why the information is needed to treat him/her and to obtain specific authorization from the patient to access the necessary information. It seems to me that only in the narrowest of circumstances would it be ethical for a physician to refuse medical services to a patient for exercising a right given to him/her by law.

In order to comply with the Act, I **recommend**:

- a) that YHSSA take immediate steps to ensure that its electronic medical record has the necessary functionality to comply with sections 22 and 23 of the Act, including
 - i) the ability to limit access to an individual's personal health information to specific individuals, except in the case of an emergency;
 - ii) the ability to mask parts of an individual's personal health information from one or more users of the system;
 - iii) the ability to record and highlight the existence of conditions placed by a patient around the collection, viewing, use and disclosure of personal health information without providing actual access to any personal health information .

- b) that YHSSA take immediate steps to establish written policies and procedures with respect to how to deal with requests from patients to place conditions on the collection, use and disclosure of personal health information, to include steps on how and by whom the patient will be provided with information about the implications of such conditions.

In addition to these recommendations which deal with the patient's rights to control over access to and the use and disclosure of personal health information, I make the following recommendations:

- a) that immediate steps be taken to ensure that the conditions set out in the Complainant's "personal directive" be recorded, implemented and honoured in accordance with the *Health Information Act* and these recommendations;
- b) that these recommendations be shared with the Department of Health and Social Services and with all other health authorities in the Northwest Territories;
- c) that YKHSSA report back to me and to the Complainant every 60 days advising both of us as to their progress in addressing these recommendations until all recommendations have been fully implemented;
- d) that YKHSSA consult with my office before finalizing the informational packages recommended herein.

In making recommendation (a) above, I caution the Complainant that this does not protect him fully from long and, to him, seemingly pointless face to face discussions with health information providers about access to, and use and disclosure of his personal health information. He has made a choice to limit who can see or use his personal health information. All choices have consequences. One of the consequences of his decision in this regard is that he will need to have discussions with health care providers about why they need access to his information and how they will use that information so that he can give them

knowledgeable consent for that use. While I appreciate that his faith in YHSSA to protect his privacy has been shaken, he will need to find a way to balance his health needs with the legitimate needs of health care professionals to provide him effective care. He will have to deal with the additional questions that will need to be asked. The implementation of the personal directive, as currently written, will mean that he will not even be able to make an appointment to see a health care provider without explicitly giving the receptionist permission to open the basic page of his electronic medical record. He will be asked, on every occasion that he sees a medical professional, whether that person can have access to his personal health information in accordance with the role based access assigned to each of them for the purpose of providing the requested medical services. He will have to recognize that, in order to have access to effective medical services, he will have to allow some access to his records and that sometimes he will have to allow more access than he may feel completely comfortable with if he is to receive needed medical attention. And he will have to accept and acknowledge that if he refuses to allow access to his personal health information in certain circumstances, he may be faced with the reality that medical staff are unable to meet his needs. This is not a threat, and should not be used as a threat. But it is a practical reality.

I strongly suggest that the Complainant and YKHSSA find a way to address the Complainant's concerns and still allow YKHSSA to provide effective medical services to the Complainant in a professional and ethical manner. For this to happen, frankly, compromises will have to be made on both sides of the equation. I have in the past recommended mediation, and I do so again while encouraging both parties to focus on what is necessary to allow this Complainant access to medical services within the context of the system of health delivery in the Northwest Territories while at the same time respecting his rights.

SUMMARY OF RECOMMENDATIONS

1. That within three months, YHSSA develop informational brochures which outline the patient's rights with respect to the collection, use and disclosure of personal health information.
2. That this brochure be provided to every patient who seeks medical care at any health care centre operated by YHSSA for at least one year and be provided to all new patients of the clinic thereafter and that the brochures be available in clinic waiting rooms on an ongoing basis.
3. That posters be developed for posting in waiting rooms and examination rooms of the all of YHSSA's clinics to alert patients to the fact that the *Health Information Act* gives them certain rights with respect to the collection, use and disclosure of their personal health information and provide contact information for patients to contact in case of questions.
4. That materials be prepared and uploaded to YHSS's web page containing the same kind of information, in more detail than is available either on the poster or in the brochures.
5. That YHSSA take immediate steps to ensure that its electronic medical record has the necessary functionality to comply with sections 22 and 23 of the Act, including
 - i) the ability to limit access to an individual's personal health information to specific individuals, except in the case of an emergency;
 - ii) the ability to mask parts of an individual's personal health information from one or more users of the system;

- iii) the ability to record and highlight the existence of conditions placed by a patient around the collection, use and disclosure of personal health information without providing access to any personal health information;
6. That YHSSA take immediate steps to establish written policies and procedures with respect to how to deal with requests from patients to place conditions on the collection, use and disclosure of personal health information, to include steps on how and by whom the patient will be provided with information about the implications of such conditions.
 7. That immediate steps be taken to ensure that the conditions set out in the Complainant's "personal directive" be recorded, implemented and honoured in accordance with these recommendations.
 8. That these recommendations be shared with the Department of Health and Social Services and with all other health authorities in the Northwest Territories;
 9. That YKHSSA report back to me and to the Complainant every 60 days advising both of us as to their progress in addressing these recommendations until such time as all of the recommendations have been fully implemented.
 10. That YKHSSA consult with my office before finalizing the informational packages recommended herein.

Elaine Keenan Bengts
Information and Privacy Commissioner