

Developing *Legislation* **to Protect** Personal Health Information



Join in the discussion

A close-up photograph of a patient information form with a green pen resting on it. The form includes fields for Patient Name, Patient's ID No., Referring Doctor, Surname, Beneficiary Code, Sex, and Allergies. It also has checkboxes for Penicillin, Sulphonamides, and Aspirin, and a section for "Have you ever experienced, or been treated for the following conditions or disorders?" with Yes/No options.

Spring/Summer 2012

Special thanks

A special thanks to the Community Reference Group for their invaluable contributions to the content of this discussion document.

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Yukon Pharmacists' Association: Carol Yamada

Council of Yukon First Nations: Lori Duncan

Yukon Medical Association: Dr. Wayne MacNicoll

Yukon Hospital Corporation: Maureen Turner and K.D. Braden

Yukon Health and Social Services: Dr. Paula Pasquali and Liris Smith

As Minister of Health and Social Services I am pleased to move forward with the development of personal health information legislation. The legislation sets a standard across the territory for health care providers to protect our personal health information. By strengthening our right to the protection of our personal health information, our government demonstrates an ongoing commitment to building a community that respects personal privacy throughout the health care sector regardless of whether the provider is in the public or private sector. The proposed law will touch on issues that are important to all Yukoners and I invite you to get involved in the public discussion.

The purpose of this public consultation is to ensure that the proposed legislation balances our right to privacy while supporting our health care providers to manage our personal health information appropriately while providing us with the highest level of care possible. The health care sector is making greater use of electronic health information systems and we must be confident that these improvements to information management protect our privacy.

I invite you to join in the discussion and take advantage of the opportunity to learn more about protecting the privacy of personal health information and the challenges that we face in balancing this with the needs of our health care providers. This consultation will hopefully promote a vigorous discussion with health care providers and all Yukoners as health care consumers.

I wish to thank the Reference Group that provided the foundation for this important initiative and recognize the valuable contribution this group made to advance our understanding of policy issues around personal health information legislation. All members participated with commitment and spirited determination towards understanding the complexities of privacy law so that Yukon legislation could be responsive to our community needs.

I thank these individuals and organizations for the time and energy dedicated to developing the policy issues discussed in this paper. I now invite comments from all Yukoners in shaping this initiative. The input from health care providers and consumers will make certain that Yukon's personal health information legislation serves our collective interest in achieving quality health care.

Thank you for your interest and input.

A handwritten signature in black ink, appearing to read 'Doug Graham', written in a cursive style.

Doug Graham, Minister,
Yukon Health and Social Services

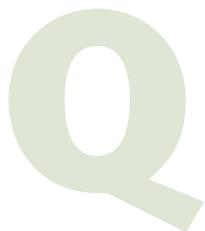
New legislation

The Government of Yukon is developing new legislation to protect personal health information. This Discussion Paper provides information about the proposed legislation and invites your comments.

This paper covers the key policy issues that will form the framework of the proposed legislation. Please note that not all details of the proposed act are discussed in this paper.

The new law must balance two things: first, your right to privacy and access to your personal health information; and second, the needs of health care providers to obtain personal health information so that they can provide you with the best health care possible.

Your input



Each section of this Discussion Paper explains one of the key issues in the proposed personal health information legislation. The Discussion Paper also proposes a way to address the issue. At the end of each section you are invited to answer questions; please see page 29 for the Response Form, where you can provide your comments.

Please provide comments on any matters that concern you. By sharing your views, you help ensure that the new legislation reflects the interests of all Yukoners.

IMPORTANT: If you provide comments, your submission will be considered a public document. Once you submit it, it will be subject to the Yukon *Access to Information and Protection of Privacy Act* and may be made available to the public.

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How you can participate

You can provide input in several ways. Written submissions, phone calls or online comments are all welcome. **Please provide your comments by July 31, 2012.**

Additional copies of this paper can be picked up at #1 Hospital Road (second floor) in Whitehorse or at the Health and Social Services office in your community. We can also send you a copy; just call us and request one.

An electronic copy of this paper is online at www.hss.gov.yk.ca/healthprivacy.php. You can download the file and type answers and comments directly into the spaces provided. If you don't wish to print the entire discussion document, you can download and print the questions only, or you can write responses on another sheet of paper and send that in.

If you require more space than is provided to respond to the questions, please continue your response on another sheet of paper. Be sure to reference the question you are responding to.

When you have completed your response, send the document to us in one of the following ways:

- Save the electronic document with your changes on your computer and e-mail it as an attachment to: healthprivacy@gov.yk.ca
- Print the document and mail it to:
Attention: Health Privacy
Health and Social Services (H-1)
Government of Yukon
Box 2703, Whitehorse, Yukon Y1A 2C6
- Print the document and fax it to 867-667-3096.
- E-mail your comments to healthprivacy@gov.yk.ca
- Call us at 867-667-5747, or toll-free in the Yukon: 1-800-661-0408, extension 5747.

Meetings can be arranged on request.

The questions contained in this document are provided as a guide. If you have other questions or comments on the proposed legislation please send them to us.

THE GOLDS

The Golds are a fictional family used in this discussion paper to illustrate some ways the proposed legislation could apply. The family members are included in stories that describe various health situations. The family consists of Grandma Sophie, Kim (mom), George (dad) and Annie (teenage daughter). Haines Junction is their home; this again is all fictional, as are the health care facilities and providers described in the stories.

Why we need this legislation

Public concern about privacy is increasing across the world. Changes to the way our personal health information is managed and shared have led governments across Canada to develop health information laws.

These laws achieve two goals:

- first, they provide protection that is specific to personal health information; and
- second, they support the ability of health care providers to have access to this information so that they are able to provide high-quality treatment and care.

Like all Canadians, Yukoners value their privacy. You want to be confident that when you share your personal information, it will be protected. You also want to know that this information will be used only for purposes that you have agreed to or that are permitted by law.

This is particularly important in the health sector because of the highly sensitive and personal nature of the information. The proposed Yukon law will apply to your personal health information when it's collected for the purpose of providing you with health care.

Personal health information legislation protects two important rights:

- your right of access to your personal health information, including your right to examine, copy and request corrections to that information; and
- your right to be assured that your personal health information will be collected, held securely, used and disclosed only according to the law.

The new legislation also introduces a new concept of “consent” for the collection, use and disclosure of your personal health information. This concept provides individuals with much greater control over their personal health information than has previously been available.

There is no specific Yukon legislation that addresses personal health information. Although your information may be protected by territorial or federal law, in some cases it may not be protected at all.

The basics

Your personal health information will be secure and protected.

Health care providers need to manage your personal health information so that they can provide you with the best possible quality of care.

You have the right to know what your personal health information can be used for and who has access to it.

Health care providers must collect only the personal health information necessary to provide you with care or as permitted by law.

Protecting privacy

One of the key principles of the proposed legislation is that personal health information must be treated in a way that protects privacy and used only for purposes that are authorized either by you or by the law.

A law that protects privacy means that personal health information is used only when necessary and only in the most limited circumstances. For example, if you injure your shoulder, your physiotherapist may need your x-rays, but would likely not need access to your mental health history. The proposed law would allow your physiotherapist to have access to the necessary and appropriate information to provide you with care, unless you disagree.

A law that protects privacy should also set standards for security of information. These standards would include authorization for access to your personal health information and security measures such as encryption of personal health information when it's being transmitted electronically.

Ten important principles

The Canadian Standards Association has developed the Model Code for the Protection of Personal Information. The Code forms the basis of legislation in many jurisdictions and has been used to develop the framework discussed in this paper. The Code includes ten important principles:

1. Accountability
2. Identification of purposes
3. Consent
4. Limits to collection
5. Limits to use, disclosure and retention
6. Accuracy
7. Safeguards
8. Openness
9. Individual access
10. Challenges to compliance

The full Code can be found at: www.csa.ca/cm/ca/en.privacy-code/publications/view-privacy-code.

Key issues that need to be addressed in the new legislation

Purpose of the legislation

The purpose of the proposed legislation is to balance two fundamental elements:

- the need to protect privacy of personal health information; and
- the needs of health care providers to appropriately collect, use and disclose the information so that they can provide health care and manage the health care system.

What the legislation could say

This is how the section related to purpose could be written in the legislation:

The purpose of the proposed personal health information legislation is to manage the collection, use and disclosure of personal health information in a way that recognizes the right of individuals to privacy and

security of their personal health information and the needs of health care providers to collect, use and disclose personal health information to support the effective provision of health care, and planning and management of the health care system.

What do you think?

See page 29 to respond to these questions.

1. Are there other basic elements that need to be considered in the overall development of this new legislation?
2. Is the balancing of these two elements appropriate or should the legislation give more weight to one of them?

What is personal health information?

The proposed legislation will address two important concepts: the type of information (“personal health information”) that the legislation applies to and the people and organizations (“the custodians”) who are regulated by the legislation.

The proposed legislation will not apply to all personal health information all the time. It is limited in scope to certain types of health information held by specific health care providers. The term “personal health information” identifies the data that is within the scope of the legislation.

Health information is only considered “personal” information when it identifies you. Here are some examples:

- information about health care services you’ve received, such as tests or lab work, including any samples of blood or tissue that carry identifying information; and
- information that relates to your health condition.

What is NOT personal health information?

Personal health information can be processed to remove any personal identifiers. For example, researchers may need to know the total number of people in the Yukon with diabetes, but they may not need to know the names of those people.

This type of processed information typically does not identify the person it relates to and therefore it is not considered “personal” health information. When information does not contain any individual identifiers, it is not personal health information and the proposed legislation would not apply to it.

The legislation would not apply to personal health information in all cases. Personal health information may be collected, used and disclosed for reasons unrelated to providing health care. For example, an airline company will collect medical information or personal health information related to a pilot’s ability to fly, but the company uses this information only to determine if the pilot is suitable for employment, not to provide health care.

Similarly, a school may collect health information about a child to provide a learning environment that is free from any allergens that could cause severe reactions. In that case, the information collected would not be covered under this legislation.

What the legislation could say

This is how the section related to personal health information could be written in the legislation:

“Personal health information” means individually identifying information that relates to your mental or physical health. This could include:

- information collected by your health care provider for the purpose of providing care;
- information that relates to payments or eligibility for your health care;
- your Yukon health care number; and
- your bodily substances needed to test for health care purposes.

Who is a custodian?

The legislation would not apply to everyone you share your personal health information with. It would apply only to specific health care providers who require your personal health information to provide you with health care or to manage the health care system.

In Yukon, health care providers may be part of Yukon government health services, the Yukon Hospital Corporation or the private health-care sector. Examples of health care providers include doctors, pharmacists and dentists. These people and organizations are referred to in the proposed legislation as “custodians” when they are collecting personal health information **for the purpose of providing health care**.

A custodian is someone who “guards or protects.” In the proposed legislation, a custodian is someone who is accountable for ensuring that your personal health information is secure and that it is used and disclosed only as allowed by law.

Who is NOT a custodian?

Not all health care providers collect personal health information for the purpose of providing care. For example, a doctor may be a university instructor with no clinical practice, or a nurse may work in an executive position within a professional organization. These health professionals would not be collecting personal health information for the purpose of providing treatment and care and would not be considered custodians.

Similarly, a sports organization or construction company would not be custodians under the proposed legislation. Although they collect health information about their athletes and employees, it is for emergency purposes and not for the provision of care.

What the legislation could say

This is how the section related to custodians could be written in the legislation:

“custodian” means any of the following who have custody or control of personal health information **for the purpose of providing health care** or the planning or management of the health care system:

- a health care provider;
- a health facility;
- the Yukon Department of Health and Social Services; and
- any other person or organization identified in regulation.

“health care provider” means a person registered or designated under Yukon legislation to provide health care, such as:

- doctor;
- nurse;
- dentist;
- optometrist;
- pharmacist; or
- another health provider who may be identified further in regulation.

“health facility” means a person or organization who operates

- a hospital, medical clinic, community health centre, dental clinic, medical laboratory or pharmacy;
- a clinic or facility that routinely provides health care diagnostic testing or procedures; and
- any other clinic or facility where health care is provided and that is identified in regulation (this could include non-government organizations that provide health care).

THE GOLDS

Annie Gold went to Whitehorse for a soccer tournament. During a game, she took a bad fall and was taken to the hospital. Fortunately, her coach had the forms her parents filled out at the beginning of the season, which had all her health information, including her serious allergies.

The coach went with Annie to the hospital and the x-ray clearly showed a broken ankle. Dr. Smith would be doing the surgery to set the break.

When the coach met Dr. Smith, the doctor appreciated having the extra information. Annie had allergies that were important to know about so that the doctor could safely give her the pain medications she needed.

How could this law apply?

Under the proposed legislation the coach would not be considered a custodian because the health information he collected was not used for the purpose of providing health care. This means that when Annie's personal health information was held by her coach, it was not protected any privacy law.

When the coach gave the information to Dr. Smith, however, the doctor became the custodian of the personal health information. He would be required to protect the information according to the law.

What do you think?

See page 29 and 30 to respond to these questions.

1. What other health care providers should be covered by this legislation? Should alternative health care providers such as naturopaths be considered custodians?
2. What agencies or community service organizations should be considered custodians?

Protecting personal health information

You want to know that when your personal health information is collected, it is secure and your privacy is protected.

Custodians are responsible for protecting the personal health information they collect from you. They can do this in several ways:

- administrative practices, such as operational policies, privacy and security training for staff, and the use of confidentiality agreements;
- technical safeguards, such as use of passwords for access to electronic files and encryption of electronic records; and
- physical controls, such as locking file rooms and shredding personal health information that is no longer needed.

It is also important for each custodian to identify an individual in each workplace who is responsible for the privacy and security of personal health information. This individual might also be responsible for developing privacy and security

policies and procedures. Clarity is an important part of building confidence in the way your personal health information is managed and making this information available to patients or clients is important.

What the legislation could say

This is how the section related to protecting information could be written in the legislation:

Custodians must establish practices that meet nationally accepted standards to manage the confidentiality, security, accuracy and integrity of the personal health information they collect. Custodians must make information about their privacy practices available to you.

The information practices should include:

- limits on the use of personal health information to only those people authorized by the custodian;
- identification of an individual to be responsible for the protection of personal health information;

- controls such as passwords so that only authorized people have access to personal health information; and
- a system that records who has looked at your personal information, if possible — for example, a log system would be required for all electronic record systems, but not for paper systems.

Custodians must ensure that the personal health information that they collect is as accurate as possible.

Custodians must let you know where your records are held, and if the records are transferred, where they will be. If your records are transferred, a custodian may transfer them only to another person who is legally authorized to receive them.

THE GOLDS

Kim Gold made an appointment at the Haines Junction Health Centre so she could go over her recent test results with her doctor. The health centre is a busy place, with people visiting and patients coming and going. First thing in the morning, the staff members pull up all the patient information that's needed for that day. This makes it faster to see patients. Sometimes this is on the computer; at other times, the files are placed on a desk for the nurses to pick up.

The day Kim made her appointment was very busy and the receptionist had to help out with an emergency. Her computer was on and the monitor was visible to people in the waiting room. She had pulled up Kim's medical record to check whether the lab reports were in. Kim's full medical record was open on the computer screen when the receptionist was called away from her desk. When Kim walked up to the desk to let them know she was there for her appointment, she could see her records and her confidential personal health information. Kim looked around the waiting room and wondered how many other people might have seen this information. Kim was visibly upset when the receptionist returned to her desk. The health centre is a busy place, but there should be privacy controls in place that make sure patient information is protected. Office efficiencies should not come at the expense of patient privacy.

How could this law apply?

Patient care is important, but so is privacy. Information practices should be reasonable for both the providers and patients. Practices such as limiting access to personal health information with passwords or arranging computer screens for controlled viewing are basic security practices and should be expected at any health care office where personal health information is regularly being collected.

What do you think?

See page 30 to respond to these questions.

1. Should some personal health information be given more protection than other personal health information? If so, what information and how would that be determined?
2. The health care sector is moving to the use of electronic health records. Do you have any particular concerns with this information management system that may be different from those related to the paper record system?

Access to personal health information

Most privacy legislation in Canada include provisions to ensure that, with few limitations, you have access to your personal health information. You can request access to your record from any custodian who you believe may have your personal health information.

If your request for access to your record is refused, the custodian must give you a reason. The refusal may be to protect you or other people referred to in your record. For example, a husband who has expressed concerns to his wife's doctor about his wife's unusual behaviour may not want her to see his comments, which could harm their relationship. If the wife asked the doctor to see her health record, the doctor would need to consider this issue and decide whether to release the entire record or remove some information.

You have a right to have access to your record within a reasonable length of time of your request. The legislation is proposing that this time period be 30 days; however, it could be extended for a reasonable period if the custodian requests it.

If you believe your record contains inaccuracies, you have a right to see a note made in your record. Inaccuracies include an incorrect date of birth; in more serious cases, you may disagree with an assessment or diagnosis on your record. Professional standards for health records limit what can be changed in a record. If you and the custodian disagree about something contained in your record, the custodian must place a note in the record.

What the legislation could say

This is how the section related to access could be written in the legislation:

You have a right of access to your personal health information.

Your request for access must be made to the custodian and must include enough detail for the custodian to identify you and the personal health information you are requesting.

The custodian must respond to your request within 30 days or as allowed by law.

A custodian may limit your access to your personal health information under certain conditions, such as these:

- the custodian believes that your knowledge of the information might endanger the mental or physical health or safety of you or another person;
- disclosure of the information would reveal personal health information about another person who has not agreed to the disclosure; or
- disclosure of the information could identify another person who provided information confidentially.

When you are given access to your personal health record, you have a right to request that your record reflect corrections or comments you may have regarding anything that you consider an error or omission on your record. The custodian must include a notation on your record.

THE GOLDS

Annie Gold's broken ankle took months to heal. She missed the rest of the soccer season, and was still in a lot of pain. George and Kim decided that they would like Annie to see another doctor. The family was going to Vancouver in a couple of months and Kim connected with a friend there who could help with a referral to an orthopedic doctor.

Kim called the Whitehorse hospital and asked if the hospital would send Annie's medical record from the surgery. The hospital administrator sent Kim the request forms to fill out and the estimated cost that would be charged for the service. Kim filled out the forms and sent in the money. Sometime later, Dr. Smith called Kim to discuss the request for Annie's medical record. Dr. Smith explained to Kim that ankles often don't heal 100%. Kim felt uncomfortable about being contacted by the doctor.

A month passed and Kim still hadn't received Annie's record. The family would be heading south soon and Kim wanted to make sure she had all the information for the Vancouver doctor to look at. She called the hospital again. They apologized for the delay, but wanted know why she was asking for the records. Kim didn't like being asked questions by the hospital and was concerned that she wouldn't have the records before the family left. Kim found out that she could ask the Information and Privacy Commissioner to help her. Fortunately, the Commissioner was able to contact the hospital and remind them of their duty to provide patients with access to their records without asking any questions or informing the various health care providers who were involved with the patient.

How could this law apply?

Kim did what was necessary to obtain Annie's records. Kim did not need to provide a reason for the request and the doctor should not have contacted her to discuss it. When Kim had difficulties that were not being addressed, the Information and Privacy Commissioner had the authority to assist.

What do you think?

See page 31 to respond to these questions.

1. Under what circumstances should a custodian be able to refuse access?
2. Is 30 days a reasonable time for custodians to deal with requests? If not, what is reasonable?
3. Is it reasonable for a custodian to charge a fee for you to access your record? Why? What could be reasonable?

Consent

The word “consent” in this proposed legislation refers to your ability to control your personal health information. This is different from consent for treatment and care that you may have also provided. Consent in this legislation is a new concept and could allow individuals to have greater control over their personal health information.

Implied, knowledgeable consent

A common approach to consent in health care is the use of implied, knowledgeable consent. The word “implied” means that your consent does not have to be spoken or written down. It means that your custodian can assume your consent when it is reasonable to do so. In other words, if you go to a doctor’s office and talk to your doctor willingly, he or she can assume that you consent to the collection, use and disclosure of your personal health information for the purpose of treatment and care.

When the law requires consent to the collection, use or disclosure of your personal health information, it is proposed that implied, knowledgeable consent be required. The “knowledgeable” part of the consent is commonly used in laws across

Canada. It has the following components:

- your consent must be voluntary, not forced, and must relate to the circumstances;
- your consent must be given by you or someone who is authorized by you;
- you know the purpose of collection, use and disclosure of your personal health information;
- you know that you may refuse or withdraw consent at any time and you know the consequences of doing so;
- you know that without your consent, information can be collected, used and disclosed only as the law permits; and
- if your personal health information is disclosed outside Yukon it will be subject to the laws of the jurisdiction where the information is received.

In certain circumstances it is appropriate that the collection, use and disclosure of personal health information be permitted without your consent.

There may be times when someone is unable to give consent, either because he or she is not competent to do so or is unable to communicate (for example, a person who is unconscious after a car accident). In these circumstances health care providers could not assume consent; however, they may be able to collect the information they need from other sources, such as other people at the scene of the accident, or close friends or family who know the person's medical history.

There may also be times when sharing someone's personal health information without his or her consent is necessary for other reasons, such as public health (for example, in cases of communicable diseases). The proposed legislation must address these situations to make sure the public interest is balanced with the right to privacy.

What the legislation could say

This is how the section related to consent could be written in the legislation:

"consent" includes your right to give, refuse, withhold or withdraw consent

Consent for collection, use and disclosure of your personal health information must:

- be provided by you or someone authorized by you or by the law,
- must be "knowledgeable," and
- must be given freely.

Implied, knowledgeable consent for provision of health care

Where consent is required for the purpose of collection, use or disclosure of personal health information your implied, knowledgeable consent is necessary unless the law explicitly requires your written consent.

Your consent (regardless of your age) is "knowledgeable" if you understand

- the purpose of the collection, use or disclosure;
- that you may give, refuse or withdraw consent at any point; and

- that the information can be collected, used or disclosed without your consent only where the law permits.

If it is reasonable in the circumstances, a custodian can assume your knowledgeable consent if he or she explains what this consent involves. A custodian cannot assume your consent if there is reason to believe that you may have difficulty understanding the information provided to you.

You can withdraw your consent, but not retroactively.

If you refuse or withdraw your consent, your custodian must

- inform you of the possible consequences;
- take reasonable steps to respect your decision; and
- at your request, make reasonable efforts to identify to you other custodians to whom your personal health information was disclosed over the past year.

A custodian can refuse to act on your request if it would likely endanger your health or the health of someone else.

THE GOLDS

When Grandma Sophie Gold visited the family in Haines Junction last year, she collapsed on the road. The ambulance attendants took her to the Health Centre right away. Sophie is 89 years old and doesn't see or hear as well as she used to.

When she arrived at the Health Centre, the nurse asked if there was someone in town to contact. Sophie's daughter Kim worked just around the corner at the school. The nurse called Kim and she came right over. The nurse was trying to get a history from Grandma Sophie, but it was difficult because Sophie is hard of hearing and she was in a lot of pain. When Kim came into the room, Sophie was so happy to see her and so sorry to be causing a fuss. Kim sat with her mom and calmed her and then they both listened carefully to the questions and gave the nurse as much information as possible so the nurse understood Sophie health condition.

The nurse didn't ask Sophie directly for her consent for anything or question whether Kim should be with her. The nurse understood that it was okay that Kim speak for her mother and that Kim understood what was going on. When Kim arrived and actively participated in providing personal health information about her mother, the nurse understood the actions as "implied and knowledgeable" consent to how and why Sophie's personal health information was being collected and used.

How could this law apply?

The law will establish a clear responsibility for the custodian to determine if patients are capable of consenting and to ensure that they understand what may happen to their personal health information. A custodian will have a new responsibility for providing patients with notice of how their personal health information may be collected, used and disclosed.

What do you think?

See page 32 to respond to these questions.

1. Does implied, knowledgeable consent provide you with enough control over your personal health information? If not, what type of consent would adequately protect patient privacy without creating excessive delay or burden in the provision of your health care?
2. Does this model create any operational difficulties? If so, do you have any suggestions about how to improve this model to minimize these difficulties?

Collection of personal health information

The proposed legislation can protect your privacy by limiting both how your information is collected and how much information is collected.

In general, custodians should collect your personal health information directly from you. In certain circumstances when it is not reasonable to do this, custodians should be permitted to collect your information from other sources. For example, if you had a serious car accident, and were too upset and in pain to tell the emergency room doctor details such as the medications you take regularly, the doctor could ask the nurse to contact your health centre or doctor and ask them for information. This is called “indirect collection.”

Custodians should be collecting the necessary information only to provide you with the appropriate health care. For example, your doctor may not need to know your annual salary, but might need to know whether you can afford the medications required as part of your treatment plan. Your custodian might discuss your financial situation in general terms to determine an affordable plan while not collecting detailed financial information about you.

What the legislation could say

This is how the section related to the collection of personal health information could be written in the legislation:

A custodian must collect your personal health information

directly from you except in these circumstances:

- you authorize collection from another person;
- the custodian reasonably believes that collection from you would: prejudice the purpose of collection; put you or someone else at risk; result in collection of inaccurate or incomplete information; or if collection is delayed, would mean that the quality of your care is at risk; and
- it is for the purpose of assembling a family history to provide you with health care.

A custodian must collect personal health information only to the extent necessary to satisfy the purposes that are permitted by law.

What do you think?

See page 32 and 33 to respond to these questions.

1. Does the approach to collection of your personal health information balance your right to privacy and the need of health care providers to indirectly collect information about you at times?
2. From a custodian’s perspective, are there operational concerns with the proposed law, which provides the ability to indirectly collect information under certain circumstances? Are there other times when indirect collection is necessary and appropriate?

Collection and use of health care numbers

Your Yukon health care number identifies you in the government's health care system. It is used to provide access to your personal health information and it should be treated as confidential.

Sometimes organizations outside the health care system ask for your Yukon health care number as personal identification or proof of residency. By providing these agencies with your health care

number, you may be compromising your right to privacy. Your health care number could be used to obtain information about you or to defraud the health system by stealing your identity.

What the legislation could say

This is how the section related to the collection and use of health

care numbers could be written in the legislation:

A person may collect or use your Yukon health care number only in these cases:

- for purposes related to providing you with publicly funded health care;
- for an approved health research project; or
- where permitted by another law.

THE GOLDS

George Gold was excited about a project going on in town to raise money for the soccer team. Through the generosity of a local builder, the soccer team was selling tickets to win a new home. The only catch was that you had to be a Yukon resident to be eligible (and pay \$50). If you bought a ticket, you needed to include your Yukon health care number as proof of residency.

How could this law apply?

The proposed law would not allow the volunteer group to collect your health care number. Your health care number is personal information and you need to provide it only when you're receiving publicly funded health care or as permitted by law. The volunteer group could not disqualify you from winning on the basis of your not providing your health care number. So, if you won and didn't provide your health care number, this law would help ensure you could move into your new home.

What do you think?

See page 33 to respond to this question.

1. Are there other cases where collection of your health care number should be allowed?

Use of personal health information

With your implied, knowledgeable consent, a custodian can use your personal health information to provide you with health care or as permitted by law. The word “use” includes sharing your information, as necessary, with other people working for the custodian, such as staff, volunteers, students and contractors. Sometimes the law will allow your personal health information to be used without your consent. Typically, these situations balance personal privacy with other compelling interests, such as public safety or health system planning.

What the legislation could say

This is how the section related to the use of personal health information could be written in the legislation:

A custodian may use your personal health information in these cases:

- for the purpose of payments related to health care;
- to educate staff, students, volunteers or other agents of the custodian about providing health care;
- to contact your substitute decision maker;
- for internal management of the custodian’s services, including planning and quality improvements;

- in the case of the Department of Health and Social Services, for planning and management of the health system;
- to detect or prevent fraud related to health services or benefits;
- for patient safety, risk management or improvements to the quality of services provided by the custodian;
- for a court procedure; and
- for approved research purposes.

THE GOLDS

Grandma Sophie was taken to Whitehorse hospital and Kim went with her. Sophie had broken her hip and would need surgery. When they arrived at the hospital, Sophie was admitted; Dr. Smith would be her surgeon.

The doctor explained to Kim that he had a medical student working with him who would assist with the case. The student met with Sophie and Kim to do a general examination and to confirm the information that the nurse in Haines Junction had provided. Dr. Smith reviewed the student's report and asked her to research some specific issues related to Sophie's case.

Dr. Smith recalled that he'd done surgery on Sophie's granddaughter Annie recently. Annie was highly allergic to some pain medications. Dr. Smith wanted to confirm that the allergies weren't shared by other family members.

Dr. Smith has been practising a long time and has a lot of experience. He is often requested to mentor medical students and high school volunteers. He must consider each of these situations to determine how much personal health information the student should see in order to receive an appropriate learning experience.

Medical students need to be fully involved in cases to gain experience on diagnosis and treatment. High school volunteers often just want to shadow a doctor at the hospital to get a feel for life as a doctor. Dr. Smith is responsible for determining whether it is appropriate in each situation for the student to have access to personal health information of his patients.

How could this law apply?

The law will allow a custodian to use information in defined ways. Using information includes sharing it with the staff in the office or clinic. Use also includes sharing the information with contractors or students working for the custodian. The custodian is ultimately responsible for the use of the information and must determine the appropriateness in each case.

What do you think?

See page 33 to respond to this question.

1. Which uses of your personal health information should require your consent?

Disclosure

Custodians can disclose your personal health information only for purposes related to providing you with health care and as permitted by law.

A custodian must disclose only the amount of personal health information necessary for the purpose. For example, if you require Homecare services following a hospital stay, the hospital may provide a summary of your surgery to the Homecare nurse, but may not need to provide your full medical history. In some circumstances — when the public benefit of the disclosure outweighs the intrusion on your privacy; for example, during an outbreak of a communicable disease — the law permits certain disclosures without your consent.

What the legislation could say

This is how the section related to disclosure could be written in the legislation:

A custodian may disclose your personal health information with your consent or that of your substitute decision maker, or as allowed by law. If your consent to disclosure is required and you have indicated any limitations on what information may be disclosed, your request must be respected where reasonably possible.

A custodian can disclose personal health information without your consent only where the law permits. The disclosure must be limited to the least amount of personal health information to satisfy the purpose for the collection. The disclosure also has to be to an appropriate person who is authorized to collect the information.

Permitted disclosures without your consent could include these circumstances:

For health care purposes if the disclosure is:

- to a health care provider who may provide your care;
- for the purpose of contacting someone who is authorized to act on your behalf or a close friend or relative, when you are unable to do so yourself;
- related to a health or safety threat to you or the public;
- to determine or verify your eligibility for health care
- about an individual who has died, or is believed to be dead, and the disclosure is necessary:
 - to identify the individual;
 - to inform the family or a friend of the death; or
 - for close relatives or other individuals, if the custodian believes the person may require the information to make decisions about his or her own health.

For health system planning and management purposes if the disclosure relates to:

- the management of payments for health care by a government in Canada; or
- a Canadian jurisdiction in which you are resident and for the purpose of health system management and planning.

For legal proceeding purposes or law enforcement if:

- in response to a summons or similar requirement;
- the custodian is expected to be a party or witness to the case; or
- the information is required for use in a prosecution or anticipated prosecution.

For institutional placements if:

- the disclosure is to a custodial institution (such as a jail or care facility) where the individual is being placed or held, to allow arrangements for services to him or her.

For the purpose of national health analysis if:

- the disclosure is through an agreement with a recognized health data institute (such as the Canadian Institute for Health Information or similar institute approved by the Minister) that assists in the development of the Canadian health system.

For business purposes if the disclosure is to:

- collect a debt owed by someone to the custodian and the disclosure is limited to contact information;
- a potential successor of the custodian, to allow a business evaluation of the operation; or
- another custodian for the purpose of transferring records.

For quality assurance purposes:

- for peer review by health professionals; or
- to ensure quality or standards of care of a custodian or within a custodian's organization.

For limited fundraising purposes by a health facility

- if you have been a patient of the facility and you have not objected to the disclosure and it is limited to your name and contact information.

THE GOLDS

Kim Gold was worried about a lump she discovered and she immediately scheduled an appointment with her doctor in Whitehorse. She didn't want to go to the Haines Junction Health Centre just in case people wanted to chat; she was too worried to visit with people.

Kim went to see her doctor in Whitehorse and tests were ordered at the hospital while she was there.

When Kim went in to the Whitehorse hospital to register at the lab, she ran into her neighbour, Dave, from Haines Junction. Dave had recently moved to Whitehorse to work as the Admissions Clerk for the lab at the hospital. Kim quickly chatted with him and gave him very general information about her health. She was very uncomfortable saying anything more than was necessary. Kim was relieved when the nurse called her in for her tests.

A few days later, Dave was typing up reports of recent tests and noticed Kim's test results. He thought he understood the results well enough to know that it was bad news for Kim and he wanted to help her out.

Dave called Kim's husband George to let him know that if the family needed anything, he'd be happy to help out. George didn't know anything about Kim's trip to Whitehorse or that she had any tests done. George was shocked, but not as much as Kim when she found out that her husband AND her neighbour knew her test results before she did.

How could this law apply?

Although Dave was trying to be helpful, his actions were not appropriate. As the Admissions Clerk, he would see many things that must be kept confidential. Discussing Kim's test results with George was an unauthorized disclosure. Dave would not have authority under the new law to discuss test results, even with Kim herself. Dave may have thought he was being helpful, but in fact, the disclosure of the information to George would be considered a breach of Kim's privacy.

What do you think?

See page 34 to respond to this question.

1. Are the circumstances outlined above appropriate for disclosure without your consent? If not, what are your concerns?

Privacy review and oversight

The *Access to Information and Protection of Privacy Act* (ATIPP) creates the position of Yukon Information and Privacy Commissioner. The Commissioner is appointed by the Yukon Legislature and is independent from government.

The Commissioner is responsible for overseeing the privacy legislation and for ensuring that people comply with it. He or she ensures that the Act is administered fairly. If you believe the Act has not been administered fairly, you can file a complaint and the Commissioner will review your concerns.

Under the proposed health information legislation the Commissioner would have

similar responsibilities to the ones currently provided under ATIPP:

- monitoring how the Act is administered;
- resolving privacy complaints;
- informing the public about the legislation;
- making recommendations regarding the legislation; and
- promoting best practice.

Under the proposed legislation, you could make a complaint to the Information and Privacy Commissioner if you believed that a custodian had collected, used or disclosed your personal health information in a way that was not authorized by legislation. You could also make a complaint if you believed that a custodian had not protected your personal health information adequately or had not provided you with the access to your personal health information that you requested.

What the legislation could say

This is how the section related to oversight could be written in the legislation:

The Information and Privacy Commissioner is responsible for monitoring how the health information law is administered, to ensure that its purposes are achieved. In that capacity, the Privacy Commissioner may perform a variety of activities. These are some of them:

- receive and review complaints from the public about the legislation and conduct investigations when necessary;
- inform and educate the public about the legislation;
- provide information to custodians about the legislation; and
- promote best practices for the protection of personal health information.

What do you think?

See page 34 to respond to these questions.

1. Are there additional responsibilities for which an independent privacy oversight body should be responsible?
2. What do you think the priorities should be for an independent privacy oversight body?

Reporting a privacy breach

When personal health information is collected, it could be lost, stolen, disclosed or used inappropriately. These occurrences are referred to as privacy breaches.

Some breaches are due to careless mistakes by custodians, such as misplacing a paper file or sending an e-mail to the wrong address. Other privacy breaches are more deliberate, such as when an unauthorized person looks at the health record of a friend or neighbour out of curiosity.

Another type of breach is when a custodian uses personal health information for another purpose that is not permitted by law without your consent. Breaches can mean that the information ends up with the wrong people or is made public. The results could range from personal embarrassment to identity theft.

Under the proposed legislation, if your privacy is breached you are notified when appropriate. The legislation would also ensure that remedies are in place to avoid similar breaches.

What the legislation could say

This is how the section related to privacy breaches could be written in the legislation:

If a custodian determines that it is unlikely the breach will result in your harm or embarrassment, the custodian does not need to notify you; however, the custodian must notify the Information and Privacy Commissioner.

The custodian of your personal health information must notify you if he or she believes that your personal health information was subject to a privacy breach and that there is potential for your harm or embarrassment.

What do you think?

See page 35 to respond to these questions.

1. Should every breach be reported or should there be criteria for determining when notice is required?
2. What factors should a custodian consider when deciding whether to notify someone of a breach?

Offences and penalties

In order to protect personal health information, there must be consequences if the legislation is not obeyed. The legislation must provide for reasonable fines and penalties. Legislation across Canada set out the activities that are considered offences and the penalties that correspond to these offences.

Potential offences

It would be considered an offence if a custodian **willfully** did any of the following:

- collects, uses or discloses personal health information, except as permitted in the proposed legislation or another law;
- destroys or changes a record with the intent to avoid a request for access to the record;
- obstructs the Information and Privacy Commissioner in performing any of his or her duties; or
- fails to protect personal health information (if he or she is a custodian of the information).

Range of fines and penalties

In other Canadian jurisdictions, fines range from a maximum of \$10,000 to \$50,000 for an individual and \$10,000 to \$250,000 for an organization or corporation.

What do you think?

See page 35 to respond to these questions.

1. Are there other potential offences not listed here?
2. What is an appropriate range for fines and penalties in Yukon for an individual and a corporation?

PLEASE NOTE: You will need Adobe Acrobat in order to save information typed into this form. If you have only Adobe Reader, you will not be able to save the information, so please print the form instead and fill it in.

Response form/questions

Please respond to questions in the space provided below, or use another sheet of paper.

Name _____ Organization (if applicable) _____

e-mail _____ phone _____

Questions: Key issues that need to be addressed in the new legislation page 8

1. Are there other basic elements that need to be considered in the overall development of this new legislation?

2. Is the balancing of these two elements appropriate or should the legislation give more weight to one of them?

Questions: Who is a custodian? page 10

1. What other health care providers should be covered by this legislation? Should alternative health care providers such as naturopaths be considered custodians?

2. What agencies or community service organizations should be considered custodians?

Questions: Protecting personal health information

page 12

1. Should some personal health information be given more protection than other personal health information? If so, what information and how would that be determined?

2. The health care sector is moving to the use of electronic health records. Do you have any particular concerns with this information management system that may be different from those related to the paper record system?

Questions: Access to personal health information

page 14

1. Under what circumstances should a custodian be able to refuse access?

2. Is 30 days a reasonable time for custodians to deal with requests? If not, what is reasonable?

3. Is it reasonable for a custodian to charge a fee for you to access your record? Why? What could be reasonable?

Questions: Consent

page 16

1. Does implied, knowledgeable consent provide you with enough control over your personal health information? If not, what type of consent would adequately protect patient privacy without creating excessive delay or burden in the provision of your health care?

2. Does this model create any operational difficulties? If so, do you have any suggestions about how to improve this model to minimize these difficulties?

Question: Collection of personal health information

page 19

1. Does the approach to collection of your personal health information balance your right to privacy and the need of health care providers to indirectly collect information about you at times?

2. From a custodian's perspective, are there operational concerns with the proposed law, which provides the ability to indirectly collect information under certain circumstances? Are there other times when indirect collection is necessary and appropriate?

Question: Collection and use of health care numbers

page 20

1. Are there other cases where collection of your health care number should be allowed?

Question: Use of personal health information

page 21

1. Which uses of your personal health information should require your consent?

Question: Disclosure

page 23

1. Are the circumstances outlined on page 25 appropriate for disclosure without your consent? If not, what are your concerns?

Questions: Privacy review and oversight

page 26

1. Are there additional responsibilities for which an independent privacy oversight body should be responsible?

2. What do you think the priorities should be for an independent privacy oversight body?

Questions: Reporting a privacy breach

page 27

1. Should every breach be reported or should there be criteria for determining when notice is required?

2. What factors should a custodian consider when deciding whether to notify someone of a breach?

Questions: Offences and penalties

page 28

1. Are there other potential offences not listed here?

2. What is an appropriate range for fines and penalties in Yukon for an individual and a corporation?

How you can participate

When you have completed your response, send the document to us in one of following ways:

- Save the electronic document with your changes on your computer and e-mail it as an attachment to: healthprivacy@gov.yk.ca.
- Print the document and mail it to:
Attention: Health Privacy
Health and Social Services (H-1)
Government of Yukon
Box 2703, Whitehorse, Yukon Y1A 2C6
- Print the document and fax it to 867-667-3096.
- E-mail your comments to healthprivacy@gov.yk.ca.
- Call us at 867-667-5747, or toll-free in the Yukon: 1-800-661-0408, extension 5747.

Please note: If you require more space than is provided to respond to the questions, please continue your response on another sheet of paper. Be sure to reference the question you are responding to.

Meetings can be arranged on request.

The questions contained in this document are provided as a guide. If you have other questions or comments on the proposed legislation please send them to us.

IMPORTANT: If you do provide comments, your submission will be considered a public document. Once you submit it, it will be subject to the Yukon *Access to Information and Protection of Privacy Act* and may be made available to the public.

Please provide your comments by July 31, 2012.

