A Guide to the Health Information Protection Act

June 1997

Alberta
HEALTH

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A Guide to the Health Information Protection Act

Table of Contents

Alberta
HEALTH

SECTION 1 - AN OVERVIEW

Introduction

Health is one of Albertans' top priorities. We all want our province to have a first rate health system with access to quality health services and constant efforts to improve the health of Albertans.

One of the most important ways of making constant improvements in health is to have better information, and then to use that information wisely to give better treatment, learn more about possible cures, find the best ways to prevent illness and injury, and improve how we manage and deliver health services.

That's one side of the coin. Getting the best information, sharing it appropriately, and using it wisely to make good decisions about how to improve health.

The other side of the coin is protecting the confidentiality of personal health information. When there are emergency situations, when our doctor is trying to find out why we're sick, or when we're searching for new cures and treatments, Albertans understand the importance of sharing health information. But they also want to make sure that confidentiality is protected, that information is shared only with those who need to know, and that their personal health information will not fall into the hands of people who will use it for the wrong purposes. With new developments in technology, it's possible to store, share and use information more readily. But it also raises more concerns about how the privacy of information can and will be protected.

The purpose of the new Health Information Protection Act is to strike the right balance - a balance between the importance of sharing information to improve health and the essential requirement of protecting the confidentiality of personal health information.

Albertans have a reasonable amount of confidence today that their health information will be protected. That's primarily because of the importance doctors, nurses and health providers place on keeping personal health information private and confidential. The draft Health Information Protection Act is an attempt to build on the strong atmosphere of trust and put clear, legislated guidelines in place.

The new legislation is built on clear principles. It sets out detailed requirements for the collection, use and disclosure of health information. It builds on similar work done in other parts of Canada and around the world. But it's not complete. Before this legislation is passed, we need the detailed advice of doctors, nurses, regional health authorities, other health service providers, researchers, and a wide range of Albertans. We need to know whether the balance is right, where there are problems, where additional safeguards may be required, or where sections of the Act could stand in the way of providing good care or improving health.

The next step is for Albertans to review the legislation and provide their advice over the summer and fall. That advice will be reflected in a revised Act, to be introduced in 1998.

The purpose of this document is to provide background on the legislation, to explain what is intended, how the legislation would work, and to raise questions in specific areas. The first part provides a general overview of the legislation and the second provides a guide to each of the major sections of the Act. We know the legislation is complex. But it's important for people to review the draft legislation so they know the details of how health information would be protected, and they can tell us if it would work well or not.

If you need more information or have questions about any of the sections of the Act or the explanations in this guide, please call Alberta Health at (403) 427-8089. You're welcome to make as many copies of this guide and the draft Act as you need.

How was the legislation developed?

In November 1996, the Minister of Health, Halvar Jonson, announced a comprehensive package called *Action on Health*. In addition to specific actions to reinvest in health and improve access, the package included a commitment to introduce legislation to protect the privacy of individual health records.

As a first step in consulting with Albertans, a discussion paper called *Striking the Right Balance* was released in December 1996. It laid out a number of basic issues involving the collection, use, access and disclosure of health information and asked for people's views on a variety of questions. Comments and submissions were received from health organizations and from individual Albertans. Interviews also were held with various health stakeholders. A summary of those consultations was released early in May 1997.

Based on those initial consultations, work began on drafting legislation. We examined similar legislation already in place around the world. We considered a series of principles known internationally as "fair information practices." We considered how information currently is collected, used and shared in the health system and for what purposes. We looked at existing health legislation and Alberta's Freedom of Information and Protection of Privacy Act.

The result of those actions is draft legislation introduced in June. But this draft legislation is just one more step in the process of developing a final product - and that's comprehensive and sound legislation to protect the privacy of individual Albertans' health information while allowing for information to be shared appropriately to improve health and Alberta's health system.

What is the purpose of the legislation?

The draft Act has the following purposes:

- to establish strong and effective mechanisms to protect the privacy of individuals with respect to health information
- to provide individuals with a right of access to health information about themselves that is held by a custodian, subject to limited and specific exceptions as set out in the Act
- to provide individuals with a right to request corrections to health information about themselves that is held by a custodian
- to prescribe rules for the collection, use and disclosure of health information, in the most limited manner and with the highest degree of anonymity possible in the circumstances
- to establish strong and effective remedies for violations of the Act
- to provide for independent reviews of decisions made by custodians under the Act and the resolution of complaints under the Act.

We expect the legislation to bring together into one Act a number of different provisions and guidelines covering the collection, use and disclosure of health information. Further work will be needed to achieve that objective but the basic framework is now available in one draft Act. To the extent possible, we also have tried to make this legislation consistent with the Freedom of Information and Protection of Privacy Act while still reflecting the unique characteristics of health information.

The draft legislation reflects some very important principles and identifies cases where exceptions can be made.

Collection limitation

There should be clear, written and publicized limits on the collection of personal health information. This information should be collected by lawful, fair, clear and pre-determined means.

Data Quality

Best efforts should be used to ensure that any personal health information collected is relevant and necessary to the purposes for which it is to be used. Personal health information should be accurate and complete.

Purpose

The purposes for which health information is collected should be lawful and publicly specified. Any subsequent use of the information should be limited to those purposes or other directly related purposes which also are specified publicly.

Limitations

Personal health information should not be disclosed, made available or used for purposes other than the approved purposes except with the informed consent of the individual or by the authority of the law.

Collection, use and disclosure of health information should be kept to the minimum amount of information at the greatest degree of anonymity possible to accomplish the approved purpose.

Where information is used or disclosed, attempts must first be made to use only non-identifiable health information. If this is inadequate for the purpose, aggregate health information may be used. If aggregate health information is inadequate, anonymous individual health information may be used. If this is also inadequate, only then may individually identifiable information be used.

Safeguards

Health information should be protected by reasonable administrative, technical and physical safeguards against such risks as loss or unauthorized access, destruction, use, modification or disclosure.

Openness

There should be a general policy of openness about developments, practices and policies regarding personal health information. Albertans and health stakeholders should be well informed about how information is collected, for what purposes, how it can be used and disclosed, and under what conditions.

Individual participation

Albertans should have a right to access health information about themselves and a right to request corrections to the information. A mechanism should exist to arbitrate disputes over accuracy.

Accounting for disclosure

Users of personal health information should be required to maintain an account of disclosures of personal health information.

Accountability

An organization holding health information is accountable for complying with these principles.

What are the key features of the legislation?

Individuals have the right to access their health information.

- According to Canadian law, individuals have the right to access their own health information. They do not own the information. The records are owned by the individual or organization that collects and keeps them. But individuals must have access to their health information.
- Individuals also have the right to request corrections to their health information if they think it isn't complete or accurate.
- Fees cannot be charged if a person wants to access their health record. But if they want copies, fees can be charged, but only to cover costs.

Custodians are responsible for maintaining, protecting and safeguarding health information.

- The draft Act designates a range of specific health providers, organizations, regional health authorities, hospitals, professional bodies, boards, agencies and the Minister of Health as "custodians" of health information.
- As custodians, these groups have responsibility for ensuring that the terms and conditions of the legislation are followed.
- Custodians have a "duty of care" and are expected to take reasonable steps to ensure that information is accurate and complete and to maintain safeguards to protect the integrity and confidentiality of health information.
- Because of their wide-ranging responsibilities, certain custodians have fewer restrictions on their ability to collect, use and disclose health information. These custodians are called "health oversight agencies." This includes the Minister of Health, regional health authorities, the Provincial Mental Health Advisory Board and the Alberta Cancer Board.
- People or agencies who receive information but are not custodians, also have a responsibility not to disclose health information and to use it only for the purpose for which it was intended.

Different kinds of information are set out.

- Health information includes a broad range of oral and recorded information about health and health services. Health information comes in several different forms, depending on whether or not it is possible to identify individuals.
- Individually identifiable health information includes all health information where an individual, family or organization can be recognized.
- Anonymous individual health information is information where an individual's identifying facts have been removed or the information has been coded to make the information anonymous.
- Aggregate health information is information about groups of individuals.
- A key principle in the draft Act is that information that cannot identify individuals should be used whenever possible. The term "non-identifiable health information" is used to describe health information where it is impossible to identify individuals. In most cases, aggregate information is non-identifiable.
- The draft Act also outlines the requirements for registration information. This includes the kinds of information needed to register people who may be eligible to receive health services. Registration information is used for a number of purposes related to managing Alberta's health system.
- Health service provider information also is defined in the draft Act. This includes information about the kinds of services different providers are authorized to provide in the province, their licensing information, and so on.

Limits are placed on the collection of health information.

- Only the necessary health information can be collected. An agency can't collect any information it might want. Instead, the information has to be clearly related to the purpose for which it is collected.
- Individuals can request that certain parts of their health information not be shared with some other health service providers. This "lock box" concept means that people can decide that sensitive health information cannot be shared with other health service providers. Some proposed legislation in other jurisdictions tries to create categories of sensitive information that are given greater protection. But information that is sensitive for one person may not be for someone else. With the lock box concept, individuals can make the decision for themselves.
- When asked, custodians are responsible for informing people about why health information is collected, how it may be used and disclosed, and how people can access their health information and make corrections when necessary. They are responsible for telling people about their option of "locking" certain types of health information, and the implications of choosing this option.

Rules are set for the use and disclosure of health information.

- Health information that is non-identifiable should be used wherever possible. Information that identifies the individual it is about should only be used where it is necessary.
- Health information may be used only for certain purposes, all of which are related to providing health services, health protection and promotion, development of public policy, and the effective management of the health system.
- Health information should be used only for the purposes for which it was collected or for a directly related purpose, unless the individual agrees. The draft Act sets out some exceptions to this overall principle.
- For disclosure of health information, the general principle is that a custodian needs prior consent in writing or in electronic form before individually identifiable health information is disclosed.
- Specific circumstances are set out for when health information can be disclosed without consent. That includes situations where disclosure is necessary to provide continuing care to the person, where it can be used to prevent or minimize danger to the individual or to others, if an individual's family needs to be informed about their condition in a hospital, so that next of kin can be identified, for peer review by professional bodies, for audits or in

a number of legal situations. Different rules apply when an individual has chosen to include certain information in a "lock box."

- Custodians have to keep a log showing disclosures of health information. This log would track all non-routine disclosures of health information. Individuals have a right to information about when their health information has been disclosed.
- The use of health information to market services or to solicit money is prohibited unless individuals consent to have their information used for those purposes.
- Non-identifiable health information may be disclosed to anyone for any purpose since there is no way individuals can be identified.
- Specific rules are set for the disclosure of health information for research purposes.

A Health Information Commissioner has the power to monitor the legislation, investigate complaints and resolve disputes.

- A Health Information Commissioner would be appointed by the Lieutenant Governor in Council to monitor the administration of the legislation and make sure its purposes are achieved.
- The Commissioner can review, investigate and attempt to resolve complaints related to access to health information, fees charged, correction of health information, or the collection, use or disclosure of health information.

There are serious penalties for inappropriate collection, use or disclosure of health information.

- There are penalties for offenses such as violating the legislation in relation to collection, use or disclosure of health information, gaining or attempting to gain unauthorized access to health information, misleading or obstructing the activities of the Commissioner, failing to comply with an order, destroying records to evade a request for access, or failing to comply with a request for information.
- The penalty for an offense is a fine of up to $50,000.

How will the legislation work?

For the most part, individual Albertans won't see major differences when they go to their doctor's office, visit a clinic or are admitted to a hospital. The responsibilities lie primarily with people who collect, use and share the information.

When you go to your doctor's office or a clinic, here's what you can expect:

- your health records will be kept safe and secure
- you can ask to review your health records, ask for corrections to be made, and ask for a copy
- unless you have asked for some of your health information to be put in a "lock box", your doctor may share information with other health providers such as colleagues, nurses, physiotherapists and specialists on a "need to know" basis so they can provide the best diagnosis, treatment and care
- at your request, your doctor will explain why health information is collected and how it may be used
- you can ask that certain parts of your health information be "locked" so that it can not be shared with some other health providers
- you can ask for information about disclosure of your health information
- you can look at your own health records and those of your children until they are 18 or mature enough to have their own right of access. You do not have access to health information about your spouse or parents unless they agree or other specific legal conditions are met.

When you go to a hospital, you can expect most of the same requirements to be met. If you're there for emergency treatment, your health information will be shared among doctors and nurses so you receive the best diagnosis, treatment and care. Information may be shared with you about the condition and treatment of family members in hospital. Your health information also will be shared if you move from one hospital to another or from a hospital into a long term care facility for the purpose of continuing your treatment.

Responsibilities of a custodian

If you are a physician, a regional health authority or any other custodian of health information, the draft Act outlines some important responsibilities for you to fulfill. Those responsibilities include:

- ensuring that the requirements of the legislation are met
- following the legislative provisions when it comes to deciding what kind of information is needed for the specific purpose involved, when it can be disclosed, to whom and under what conditions
- when asked, informing people about why health information is collected and how it will be used
- arranging for people to have access to their health information when requested, except in certain situations set out in the draft Act
- allowing people to correct their health information (except in situations set out in the draft Act) and advising other custodians (those to whom information has been disclosed) about those corrections
- advising people of their right to "lock" information so it isn't shared with some health providers
- keeping disclosure logs
- providing health information to other custodians, particularly health oversight agencies
- ensuring that administrative, technical and physical safeguards as specified by regulations to the Act are in place to protect health information
- working with researchers and having agreements in place as set out in the draft Act, if applicable.

What are the next steps?

Those are the basic requirements set out in the new Health Information Protection Act and a brief overview of how it will work. There are a number of specific detailed provisions, especially where there are exceptions to the general principles. People are encouraged to review the second part of this guide for a more detailed explanation of the legislation.

We know there are a number of issues to be addressed. And we're counting on the advice of health providers, organizations and Albertans to help develop the best solutions. Work is underway to outline the different types of information collected in the health system, how it is used and by whom, so that we can make sure the legislation covers all different health information needs. We need to work with health service providers to develop provisions for the appropriate protection and sharing of health service provider information. We need to work closely with initiatives currently underway to develop better technology solutions for managing health information across the health system. And there are a number of specific questions and issues that need to be addressed.

The next step is to listen carefully to the views of Albertans, to take their advice and the advice of those who work with health information on a day to day basis, and to build that into new legislation for 1998.

SECTION 2 - AN EXPLANATION OF THE LEGISLATION

Introduction

The legislation is divided into seven parts:

- Obtaining access to health information
- Collection of health information
- Use and disclosure of health information
- Office and powers of the Health Information Commissioner
- Reviews and complaints
- General provisions (includes offenses and penalties) and
- Transitional.

This part of the guide will explain each of those seven parts. Readers of this part may want to keep the draft legislation handy as a reference because specific sections are not included in the guide. In each part, we have raised several questions, but we encourage you to raise additional questions as well, and to provide feedback on issues that may have been missed or not adequately addressed.

Definitions and purpose of the draft Act

This section of the draft Act lays the groundwork. It sets out a clear purpose. And it defines the kinds of information to be covered, the types of individuals and organizations designated as custodians of health information, health services provider information, a health record and a number of other terms important for the draft Act.

Key definitions:

Health information

Health information includes any information about the health of an individual, health services provided to an individual, about an individual's donation of body parts or substances, information that comes from tests performed on individuals, or information collected while a health service is being provided.

Health information comes in different forms. In this draft Act, different kinds of health information have been defined based on whether or not individuals can be identified. These types include: individually identifiable health information, anonymous individual health information and aggregate health information. The term "non-identifiable health information" is used to describe health information where it is impossible to determine the identity of the individuals involved. In most cases, aggregate information is non-identifiable.

These distinctions are important because, throughout the draft Act, the principle is that information that does not identify a particular

individual should be used wherever possible. Only in those cases where it is necessary, should individually identifiable health information be used.

This is consistent with the advice we received in the initial consultations. Most people felt that different kinds of information have different levels of significance when privacy issues are involved. Disclosure of information that identifies the individual has the most serious implications for protection of privacy. On the other hand, there are few concerns about confidentiality when the information can not identify individuals.

Registration information is set out as a separate category. Disclosure and use of registration information is necessary for management purposes and most often, it is information that only needs to be collected once.

Health record

A health record includes health information in any form including x-rays, notes, images, audio-visual recordings, books, documents, maps, drawings, photographs, letters, vouchers and papers and any other information that is written, photographed, recorded, digitized or stored in any manner. It does not include software or any mechanism that produces records.

Custodian

The term "custodian" is used to refer to individuals and agencies that are responsible for collecting, using and disclosing health information. Custodians have a duty to maintain appropriate safeguards and ensure the integrity, accuracy and confidentiality of health information.

The draft Act provides an extensive list of custodians including government bodies, regional health authorities and provincial boards, hospitals, nursing homes, health professional bodies, health service providers, foundations, and government bodies. The draft Act also allows for other agencies to be designated as custodians through subsequent regulations.

At this time, private agencies are not included as custodians. Examples of private agencies with health information include insurance companies that handle prescription drug claims, life insurance companies, employers, private health care providers, pharmacists and so one. However, if private agencies provide health services funded in whole or in part by the government, the same rules governing protection of privacy would apply.

Health service provider information

A wide range of health provider information is defined in the draft Act. The intention is that clear rules for the protection, use and disclosure of health provider information would also be included in the legislation. Further work is needed with health provider groups to develop the appropriate mechanisms.

Purpose of the draft Act:

Overall, the purpose is to strike the right balance between allowing access to information to improve health and the health system and protecting the privacy of personal health information. By putting a clear framework in place, we can ensure that the balance is clear, that both the public and those working in the health system understand the rules for protecting privacy, and that the balance is maintained over the longer term.

Specifically, the purpose of the draft Act is:

- to establish strong and effective mechanisms to protect the privacy of individuals with respect to health information
- to provide individuals with a right of access to health information about themselves that is held by a custodian, subject to limited and specific exceptions as set out in the Act
- to provide individuals with a right to request corrections to health information about themselves that is held by a custodian
- to prescribe rules for the collection, use and disclosure of health information, in the most limited manner and with the highest degree of anonymity possible in the circumstances
- to establish strong and effective remedies for violations of the Act
- to provide for independent reviews of decisions made by custodians under the Act and the resolution of complaints under the Act.

Some questions to consider:

How should the legislation apply to private sector agencies? How would this be monitored?

Are the definitions and purpose clear? Have important components been missed?

Part 1 - Obtaining access to health information

Objectives

To provide individuals with the right to access their health information

To enable individuals to correct inaccurate information on their health record

To set out reasonable timelines for accessing and correcting health information

To limit the circumstances under which a custodian could refuse to give an individual access to his or her health records and set out appropriate appeal mechanisms

To enable a custodian to charge a fee to cover the costs of copying health information

Background explanation

The right of individuals to access information about themselves is an essential part of fair information practices. Information about individuals should not be kept secret; people should know what information is kept about them. Allowing individuals to access their health information also is an important way of involving people directly in their own health care.

While the draft Act gives people the right to access their health records, it does not give them ownership of those records. Current legal decisions in Canada indicate that records created and maintained by an agency are owned by that agency, but they must give access to the individuals involved. The provisions in this draft Act are consistent with current law.

Individuals also have the right to ask for corrections of errors or omissions in their health information. This is important for both accuracy and fairness. The individual is most often in the best position to know if information is accurate. And it's also a matter of fairness. Since information that is incorrect or included by mistake could have a negative affect on the individual, he or she should be able to access information and ask that it be corrected where necessary.

While access to personal health information is a right, there are specific situations in which that information could be harmful to the person's mental or physical health and safety. The legislation sets out specific cases in which custodians could refuse to grant an individual access to his or her health information.

Key provisions

- If an individual makes a request to access his or her health information, the custodian must respond to that request within 30 days. Under certain circumstances set out in the draft Act, the time frame could be extended for an additional 30 days.
- Under certain limited conditions, a custodian could refuse access to the individual's health information. These conditions include a reasonable belief that access to the information could result in immediate and grave harm to the individual's health or safety, threaten someone else's safety or mental or physical health, or interfere with public safety. Access can also be denied if the record could lead to the identification of other individuals, if the record is subject to legal privilege, or if it contains information about peer reviews or discipline proceedings. Another reason for refusing access includes cases where the information could reveal advice and recommendations to cabinet ministers.
- If an individual is denied access to portions of his or her health information for the reasons noted above, wherever possible, the custodian should extract those portions from the individual's health information and allow them access to the remainder of their health information.
- Individuals can ask for corrections or amendments to their health information if they believe there are errors or omissions. A custodian has 45 days to make the requested corrections.
- If the custodian disagrees with the requested corrections, the custodian must explain their reasons and tell the person that their decision not to make the corrections can be reviewed by the Health Information Commissioner. The individual can also choose to prepare a statement of disagreement which then must be attached to the individual's health record and disclosed whenever that health information is disclosed.

Some questions to consider

Are the provisions and timelines for access appropriate?

Are the limitations on when a custodian can refuse access clear and appropriate?

Part 2 - Collection of health information

Objectives

To limit the collection of health information to information that is necessary for specific purposes outlined in the draft Act

To ensure that, wherever possible and practical, health information is collected directly from the person it is about

To enable individuals to decide that certain portions of their health information can not be shared with other health providers without their consent

To require custodians to inform people about their right to access health information

To require custodians to maintain reasonable safeguards to protect the safety, integrity and confidentiality of health information, and to ensure that the requirements of the legislation are followed

To require the custodian to take reasonable steps to make sure health information is accurate

To require prior consent from an individual if health information is to be obtained using a recording device, camera or any other device that may be hidden from the individual, except under certain conditions

Background explanation

The basic principle is that limits should be placed on the health information a custodian collects. The custodian is expected to collect only the information it needs to achieve the specific purpose it is collecting the information for. People are concerned about custodians collecting large amounts of information for no particular purpose, then storing it for possible use in the future for some purpose not evident at the time it is collected. The ease of collecting and storing information increases with new advances in technology. But it also heightens concerns about health information being used inappropriately. By limiting the scope of information custodians can collect, we can make sure they have the information they need for the intended purpose, but we can also allay the public's concerns about information being used for other purposes.

A second basic principle is that information about an individual should be collected directly from that person except under certain circumstances. This helps ensure the information is accurate and it is also fair to the individual involved because they know what information has been collected about them.

The "lock box" provision is an important concept in this part of the draft Act. We know that some information is more sensitive than others. Information about mental health or sexually transmitted diseases may be very sensitive to the individuals involved and may cause harm to them if it is disclosed. Some legislation proposed in other jurisdictions attempts to define categories of sensitive information and provide those categories with greater protection. The difficulty comes with trying to define sensitive information. As we heard during the consultations, sensitivity depends on the individual involved. Information that is considered sensitive by one individual may not be viewed in the same way by another individual.

Therefore, we've taken the position of allowing individuals the right to declare certain parts of their health information sensitive and put a "lock" on that information. This means information that is "locked" cannot be shared with some other health providers without prior consent of the individual involved. Some very limited circumstances are provided where "locked" information can be disclosed, largely for management and statistical purposes.

At this time, the draft Act does not contain specific references to different ways health records and health information may be linked using technology. We expect, however, that the legislation will have an impact on how health information systems are developed and used. Safeguards are needed so that appropriate standards of protection, consistent with the legislation, can be built in. While technology will change over time, the principles surrounding the collection, access, use and disclosure of health information should still hold true. That is the focus of this legislation.

As part of initiatives underway in information management and information technology, a committee involving province-wide leaders in the health system, will be responsible for providing leadership in future information technology developments. A key part of their work will be to ensure that future information technology and management solutions adequately protect the confidentiality of health information and meet the requirements of the legislation.

Key provisions

- Custodians cannot collect information unless it is for a lawful purpose and necessary for that purpose.
- Information must be collected directly from the individual except under certain conditions listed in the draft Act.
- An individual may choose at any time to request that a record or part of a record not be disclosed to another health provider unless the individual agrees to the disclosure. Certain conditions are

included in the draft Act where disclosure would be required. Health service providers are required to tell people about this "lock box" provision and to advise them of the implications and the conditions under which this information could be disclosed.

- At the request of an individual, the custodian is required to inform them about their right to access health information and the procedures that should be followed.
- Rather than set particular standards in this Act, the draft Act requires custodians to take reasonable steps to maintain administrative, technical and physical safeguards to protect health information and ensure that the legislation is followed by their employees. This includes measures for the proper disposal of records.
- The custodian is required to take reasonable steps to ensure the accuracy of information before it is used or disclosed.
- If a custodian collects health information by using a recording device, a camera or any other device that is hidden from view or not obvious to the individual, they are required to get the person's written consent in advance. The only exception is if the custodian has reasonable grounds to believe that telling the person in advance and asking for their approval would result in the collection of inaccurate information.

Some questions to consider

Is the "lock box" provision sufficient to protect sensitive information? Will it have an unduly negative impact on the ability of health providers to provide quality care and treatment?

Part 3 - Use and disclosure of health information

Objectives

To set clear rules for the use and disclosure of health information

To require that, wherever possible, non-identifiable health information should be used. Individually identifiable health information should be used only where it is necessary to achieve the specific purpose involved. The same approach applies to disclosure of health information.

To limit the use and disclosure of health information to only that which is required to achieve the purpose involved

To set out specific limited conditions under which health information can be disclosed without the individual's consent

To set specific rules for the disclosure of health information for research and other specific purposes

To enable the disclosure of non-identifiable health information to any person for any purpose

To require custodians to keep a log recording non-routine disclosures of health information

To identify rules for the disclosure of information to a person or agency that is not a custodian

Background explanation

In many ways, this is the most important part of the legislation because it sets out the rules for how health information can be used and disclosed.

Several important principles are involved. First, health information can be used only for certain purposes set out in the draft Act. Those purposes are: providing health services, determining the eligibility of a person to receive a health service, planning and resource allocation, quality assurance and peer review, research, evaluation, health system management, health services provider education, public health surveillance, health policy development and monitoring and audit.

Two purposes are specifically prevented by the draft Act. A custodian cannot use health information it has collected in order to market its services or solicit money or donations, except with the prior consent of the individuals from whom the information was collected.

The second principle is that information collected for one purpose should not be used for other purposes without the permission of the individuals involved. Certain conditions are set out in the draft Act in

which information can be used for directly related or consistent purposes.

A third principle is that the most limited amount of information at the highest level of anonymity should be used wherever possible. The draft Act sets up a hierarchy of information from non-identifiable to individually identifiable information. Custodians wanting to use or disclose health information, are expected to begin with non-identifiable information and move to individually identifiable information only where it is necessary to achieve the intended purposes.

Some examples may help make the point. If, for example, researchers want to track how healthy Albertans are, they may conduct research on the average length of life of Albertans. There is no need for them to use anything but non-identifiable information since the identity of people is not necessary. If a medical researcher is conducting field trials on a new drug, he may be able to use either aggregate or anonymous information. On the other hand, in the case of some medical research, it is essential for the researcher to have first hand contact and interviews with individuals involved and to monitor their progress over time. In these cases, individually identifiable health information is essential.

Again, the principle is that the level and scope of information to be used and disclosed should be appropriate to the specific purpose involved.

A fourth general principle is that information should not be disclosed without prior consent of the individual involved. At the same time, there are a number of good reasons for sharing information, particularly when individuals cannot be identified. Those include good decision making, improved accountability and better management of health resources.

There also are specific cases in which consent is not possible, where it is in the best interests of the individual regarding treatment or continuing care, when family members need to be notified or informed of diagnosis and treatment, or in a number of other situations. Because disclosure without consent should be the exception, the draft Act specifically identifies situations in which this can happen. In cases where there is disclosure without consent, the information disclosed should be limited to only that which is necessary to achieve the purpose involved.

Key provisions

- Specific purposes for which health information can be used are set out in legislation.
- A custodian cannot use information for any other purpose unless the individuals involved have agreed, the other purpose is consistent with the original purpose, or there are specific rules allowing its disclosure without consent. The conditions for determining whether a secondary purpose is consistent with the original purpose are defined in the legislation.
- Except in the context of providing health services to individuals, a custodian is expected to try to use or disclose non-identifiable information first, then aggregate information, then anonymous information, and finally individually identifiable information only if it is essential.
- A custodian is required to use and disclose only that information that is necessary to carry out the intended purposes.
- In most cases, prior consent is required before a custodian can disclose individually identifiable health information. Consent must be in written or electronic form and include an expiry date, the purpose for the disclosure, who it is being disclosed to, an acknowledgment that the individual has been informed of the reasons, the implications of disclosure, and an understanding that consent may be revoked at any time.
- Specific conditions have been set in legislation for when health information can be disclosed without the consent of the individual involved. These exceptions relate to the following situations:
  - continuing treatment for the individual
  - informing family or close friends about an individual's location, condition, diagnosis, progress and prognosis, on a specific day unless it is contrary to an individual's express request
  - transferring information from one custodian to a successor custodian
  - providing information to an official of a penal or other custodial institution in which an individual is being lawfully detained if the purpose is to provide health services to that individual
  - for the purposes of an investigation, discipline proceeding or practice review by a health professional body (this information cannot be disclosed to anyone else not involved in the review and must be destroyed at the earliest opportunity)
  - for an audit (same conditions apply as to reviews by health professional bodies)
  - the information is already available to the public

- for a court proceeding or a proceeding before a quasi-judicial body
- for an officer of the Legislature so that the officer can perform his or her duties
- cases where the custodian believes disclosure would avoid or minimize an imminent danger to the health or safety of any person
- informing the next of kin or a friend of an injured, ill or deceased individual unless it is contrary to the express request of the individual
- cases where the individual lacks the mental capacity to provide consent and disclosure is in the best interests of the individual
- where disclosure is required or permitted under another Act in Alberta or Canada
- complying with a subpoena, warrant or other order
- providing information to the personal representative of a person who has died for the purposes of administering the estate.

- Registration information can be disclosed without the consent of the individual for the purposes set out in the legislation.
- Under certain conditions, the Minister of Health may disclose registration information to another ministry of government without the consent of the individuals involved. In these cases, an agreement must be in place which requires the recipient of the information to use the information only for the purposes outlined in the agreement. The Minister also may disclose health information without the consent of individuals involved for the purpose of administering health legislation or allocating resources for health programs and services. This would include cases where the Minister is required to make decisions about treatment and care such as support for out of country or out of province care. The Minister also may disclose information to other departments without the consent of the individual if the disclosure is for the purpose of developing public policy. As is the case for all custodians, the Minister must meet the same tests of using individually identifiable health information only when it is necessary.
- Specific conditions are set out for the disclosure of health information without an individual's consent for research purposes. Only certain custodians can disclose health information for research purposes. That includes the Minister of Health, regional health authorities, the Alberta Cancer Board and the Provincial Mental Health Advisory Board. Where individually identifiable information is required for the research project, custodians are

required to determine that the research project is of sufficient public interest to outweigh the normal requirements for protection of privacy under the legislation. This involves considering whether the research will contribute to prevention or treatment of illness or injury, scientific understanding related to health, promotion and protection of health of individuals and communities, the improved delivery of health services, or the improved management of the health system. Agreements must be in place between the custodian and the researcher. Those agreements would set out conditions and safeguards for protecting health information. If a researcher wants to make contact with individuals who the information is about, the custodian is required to get the individual's consent first.

- Because of the extensive responsibilities of certain custodians, they have been designated as "health oversight agencies" and given additional powers to use, disclose and require disclosure of health information from other custodians. The list of health oversight agencies includes: Minister of Health, regional health authorities, the Cancer Board, the Provincial Mental Health Advisory Board and any body designated in the regulations. The Minister may require health information from any custodian while the others may only require the information from a custodian that they fund. Health oversight agencies have additional powers to use information, disclose information to other health oversight agencies, and compel information from custodians.
- Each custodian is required to keep a log showing non-routine disclosures of health information. This excludes routine disclosures of health information such as providing information to Alberta Health for billing purposes or for health care insurance. Individuals have a right to information about when their health information has been disclosed.
- When custodians disclose information, they must take reasonable steps to ensure that the recipient of the information knows that the information must not be used or disclosed for any purpose other than the purpose for which it was disclosed to the recipient.

Some questions to consider

Are the purposes set out in the draft Act for the use and disclosure of information too narrow or not narrow enough?

Is the balance right regarding disclosure of health information? Are the provisions for disclosure without consent too extensive? Do they cover reasonable situations in which disclosure without consent would be justified?

We have required custodians to keep a log of non-routine disclosures. Should all disclosures, routine and non-routine, be included? Should they also have to keep a log of each time health information is accessed?

Are there other agencies or organizations that should be designated as health oversight agencies?

Should the lock box provision extend to health oversight agencies?

Should custodians have to obtain consent before researchers can contact subjects for bona fide health research activities?

What kind of administrative burden will be placed on custodians? Is it reasonable?

Should provisions be included to cover responsibilities when information is

linked and shared through technology?

Part 4 - Office and powers of the Health Information Commissioner

Objectives

To establish a Health Information Commissioner with the responsibility of monitoring administration of the legislation and ensuring that its purposes are achieved

Background explanation

In the consultation process, most respondents said there was a need for an independent third party to oversee the legislation, arbitrate disputes and investigate complaints.

Under the proposed Act, a Health Information Commissioner would be appointed by the Lieutenant Governor in Council. The Commissioner would be an officer of the Legislative Assembly, much the same as the Information and Privacy Commissioner under the Freedom of Information and Protection of Privacy Act.

The legislation sets out how the Commissioner would be appointed, the term of office and conditions of employment, and specific powers and duties.

Key provisions

- The Commissioner is generally responsible for monitoring how the legislation is administered to ensure that its purposes are achieved.
- Specifically, the Commissioner may:
  - conduct investigations to ensure compliance with the legislation
  - make an order
  - inform the public about the legislation
  - receive comments from the public regarding the administration of the legislation
  - engage in or commission research
  - comment on health protection implications of using or disclosing health information for linking health records using technology
  - authorize collection of health information from sources other than the individual involved
  - give advice and recommendations to custodians.
- An Office of the Health Information Commissioner may be established as part of the public service with employees necessary to fulfill the functions of the Commissioner.
- The Commissioner may investigate and attempt to resolve complaints involving access to health information, inappropriate fees, refusal to correct health information, or the inappropriate

collection, use or disclosure of health information.

- In conducting an investigation, the Commissioner has all the powers, privileges and immunities of a commissioner under the Public Inquiries Act.
- Information provided to the Commissioner is, with some exceptions, not admissible as evidence in any court proceedings. Anything said or any information or records provided to the Commissioner during an investigation or inquiry is privileged information. The Commissioner and anyone working for the Commissioner may not disclose this information except in certain specified instances.
- The Commissioner and those acting under the Commissioner cannot be sued for actions they have taken in good faith under the legislation.
- The Commissioner must provide an annual report on the work of the Commissioner's office.

Some questions to consider

Is this an appropriate mechanism for investigating and resolving complaints? If not, what alternative is better?

Are the powers sufficient to allow the Commissioner to ensure that the purposes of the draft Act are achieved?

Would it be appropriate for the duties of the Health Information Commissioner to be fulfilled by the Office of the Information and Privacy Commissioner?

Part 5 - Reviews by the Commissioner

Objectives

To provide effective mechanisms for individuals to request a review of decisions made by a custodian or other matters specified in the draft Act

To set out a process of mediation as the first step to resolving disputes

To set out the timelines and requirements for inquiries under the legislation

To set out a further process for review of the Commissioner's decisions by an adjudicator

To set clear rules for the disclosure of information to the Commissioner

Background explanation

This part sets out processes and timelines for individuals to request a review by the Commissioner. When a request is received, the Commissioner may investigate the complaint and try to resolve the matter through mediation. If mediation fails, an inquiry must be held and decisions made by the Commissioner.

The draft Act also sets out a further stage of review if it can be shown that the Commissioner had a conflict of interest in making a decision. In this case, an adjudicator would be appointed by the Lieutenant Governor in Council.

Finally, the legislation sets out rules for disclosure of information to the Commissioner. The key points are that an employee of a custodian may disclose information to the Commissioner if he or she, acting in good faith, believes there has been a violation of the legislation. An employee who makes this type of disclosure is not liable for prosecution under the draft Act and the individual's employer is not allowed to take any employment action against them.

Key provisions

- An individual or the relative of a deceased person may ask for a review by the Commissioner.
- The request must be in writing. It should be made within 60 days of the decision of a custodian that is the subject of the review. The Commissioner may extend the timelines.
- The Commissioner is required to give a copy of the request for review to the custodian involved and any other person affected by

the request and to provide a summary of the review procedures to all parties involved.

- The Commissioner may ask a mediator to try to resolve the complaint. If that is not successful, an inquiry must be held.
- The individual who requested the review may be represented at the inquiry by counsel or an agent. The inquiry must be completed within 90 days after receiving the request for the review except in certain circumstances.
- If the inquiry relates to a decision to refuse an individual access to all or part of his or her health record, the onus is on the custodian to prove that the individual has no right to the health information.
- At the completion of the inquiry, the Commissioner must make an order outlining his decision. The Commissioner's order is final. The order of the Commissioner may be filed with the Court of Queen's Bench and then it becomes an enforceable order of the Court.
- The custodian must comply with an order of the Commissioner within 30 days.
- If an individual affected by a Commissioner's decision feels the Commissioner was in a conflict of interest, the draft Act includes provisions for appointing an adjudicator. Conflict of interest involves situations where the Commissioner was a member, employee or administrator of the custodian whose decision is involved or other conflicts of interest with a custodian. The request for an adjudicator must be in writing and delivered within 60 days after the decision by the Commissioner. The adjudicator's powers are set out in the draft Act.
- An employee who thinks there may have been a violation of the legislation can disclose information to the Commissioner. The Commissioner must investigate. The employee can not be prosecuted for disclosing information under the draft Act. Also, their employer cannot take employment action against them and, if they do, they are liable for a fine of up to $10,000.

Some questions to consider

Are the provisions for reviews by the Commissioner sufficient?

Are the timelines reasonable?

Part 6 - General provisions

Objectives

To set out procedures for giving notice

To describe conditions under which an individual's rights can be exercised by someone else

To authorize employees to carry out duties under the legislation

To set out limitations on legal actions against the Crown, custodians and health oversight agencies

To set appropriate penalties for violations

To outline the power to set regulations and assess fees

Background explanation

There are several key features in this part. The first sets out situations in which an individual's rights can be exercised by someone else. Generally, anyone over the age of 18 has the right to exercise the rights themselves. If an individual is under 18 but can understand the rights they have and the consequences, they may exercise the rights themselves. Other situations are set out in the legislation.

This part also contains provisions respecting notice, fees, offenses and penalties, and the power to make regulations.

Key provisions

- Notices or documents may be given by mail, personal service, or by electronic transmission.
- The rights of an individual may be exercised by someone else if the person is under 18 and not mature enough to understand the rights involved, if a person is deceased, by a guardian or trustee appointed under the Dependent Adults Act, if power of attorney has been granted, or if there is written consent by the individual involved.
- No action or suit can be brought against the Crown, a custodian or a

health oversight agency for damages resulting from actions taken in good faith under the legislation.

- No person shall collect, use or disclose information in violation of the legislation, gain or attempt to gain unauthorized access to health information, make a false statement or mislead the Commissioner, obstruct the Commissioner in the performance of duties, fail to comply with an order of the Commissioner, destroy records to avoid a request under the Act or fail to comply with a notice by a health oversight agency. A person who violates the legislation is subject to a fine of up to $50,000.
- The Lieutenant Governor in Council may make regulations designating additional agencies as custodians, respecting the steps a custodian must take and conditions related to disclosure of information for research purposes, designating a health oversight agency or respecting fees to be paid.

Some questions to consider

Are the offenses and penalties clear and appropriate?

Are the circumstances for having someone else exercise an individual's rights appropriate?

Part 7 - Transitional and commencement

This section of the draft Act provides for the appointment of the first Health Information Commissioner. The legislation is intended to come into force on proclamation.