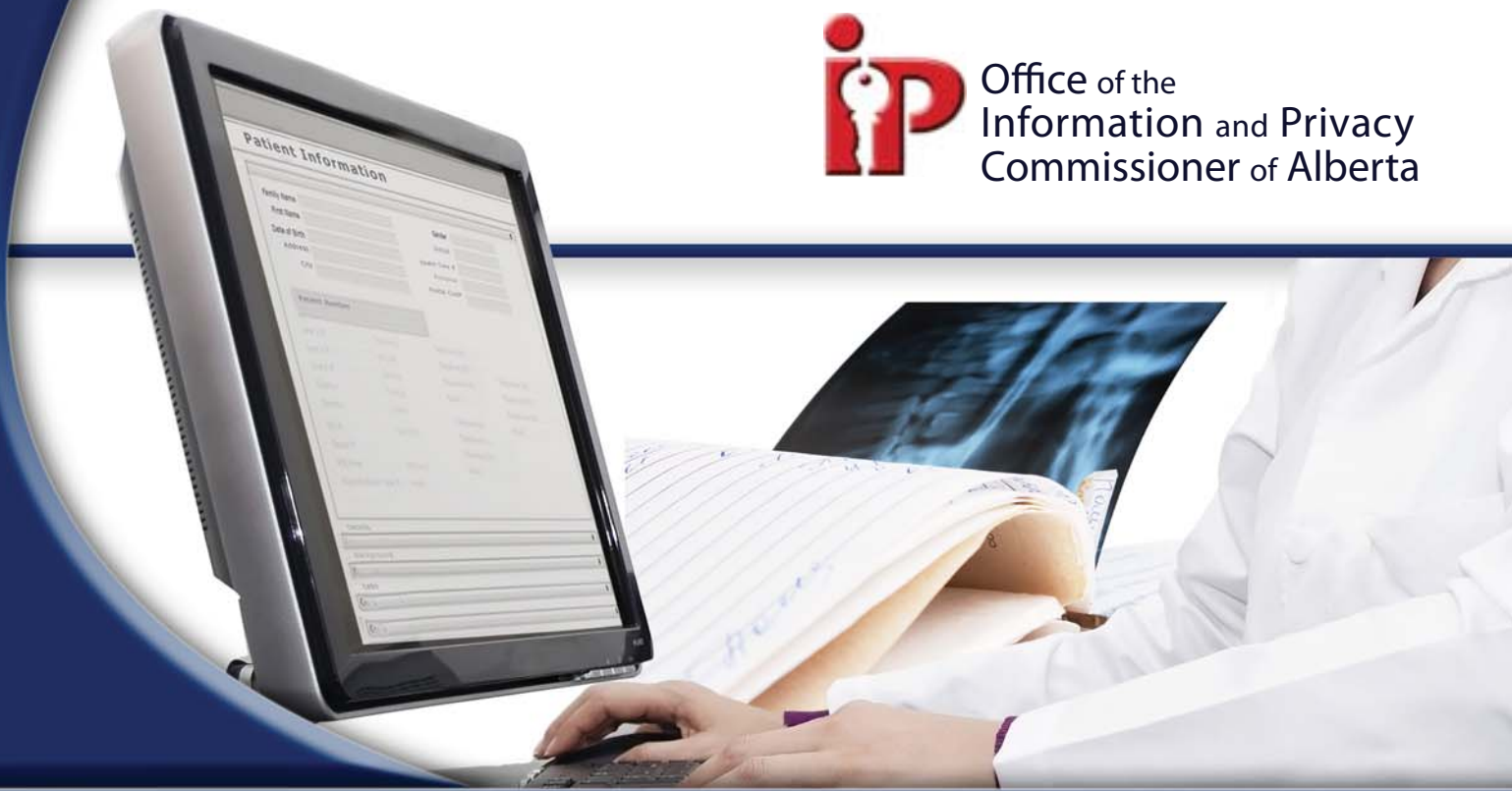
HEALTH INFORMATION
A PERSONAL MATTER

A Practical Guide to the
Health Information Act



Office of the
Information and Privacy
Commissioner of Alberta

Promoting a society where personal information is respected and public bodies are open and accountable

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DISCLAIMER

This practical guide is based on the *Health Information Act* and regulations. It refers to or paraphrases provisions from these enactments. Do not rely on the paraphrases in this guide. It is strongly recommended that this guide be used in conjunction with the *Health Information Ac*t. Always refer to the specific legislation for the text of the provisions.

This publication is provided as information only. All examples used are provided as illustrations. This publication is not to be used as a substitute for legal advice. This guide is not an official interpretation of the law and is not binding on the *Office of the Information and Privacy Commissioner*.

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Office of the
Information and Privacy
Commissioner of Alberta
410, 9925 – 109 St.
Edmonton, AB T5K 2J8
Tel: (780) 422-6860
Fax: (780) 422-5682

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HEALTH INFORMATION
A PERSONAL MATTER

A Practical Guide to the *Health Information Act*

Office of the Information and Privacy Commissioner of Alberta

THE PURPOSE OF THIS GUIDE

This guide is intended to give *custodians* a basic understanding of the *Health Information Act* (HIA or the Act), specifically in those areas that have changed or are new to the Act including the areas they are most likely to encounter in the course of their practice or employment.

This guide is not intended to be an exhaustive study of the Act and will not provide answers to every question that might arise in practice. It points out the major duties and powers created by the Act and the rules governing how those duties are to be fulfilled and how those powers are to be exercised.

Examples are given of situations that might arise in practice and suggestions are made about how the Act might apply. This guide is not a substitute for legal advice. If you are unsure about whether or how the Act applies, you should contact your HIA co-ordinator, professional college or association, Alberta Health and Wellness, the *Office of the Information and Privacy Commissioner,* or a lawyer.

Important points made in this guide are printed in boldface type. Some words or phrases are printed in italics. Italicized words or phrases have a specific meaning in the Act. The glossary at the end of the guide will provide those definitions. When you are trying to decide if or how the Act applies, it is extremely important to pay attention to the definitions in the Act. Many of these definitions have changed and they are crucial for determining even basic issues such as whether you are subject to the Act or not.

TABLE OF CONTENTS

INTRODUCTION to the *HEALTH INFORMATION ACT* (HIA)

The *Health Information Act* sets out rules governing the collection, use and disclosure of *health information*. These rules apply to all *custodians*, including *health services providers* who have been designated as *custodians* in the regulations. The details concerning a person's health status have long been considered the most sensitive type of information. Concerns about the privacy and confidentiality of *health information* are common to us all. At the same time, there is a strong view that *health information* can be used to provide caregivers better information about people who need *health services*, survey the health of Canadians, define the determinants of our health and better manage our health care system. While the HIA provides for these uses of *health information*, it also affirms prevailing professional ethical obligations respecting confidentiality and security of *health information*.

The HIA also provides a right of access by individuals to their own *health information*, and a right to request a correction of their *health information*.

Since the introduction of the HIA, a number of changes to the Act have been passed. The scope of the Act has been expanded to include *health information* about all *health services* provided by *custodians* regardless of how the *health service* was funded, and includes new types of *custodians*. The introduction of the Alberta Electronic Health Record and ability for the Minister of Health and Wellness to designate a *Health Information Repository* are two new parts to the Act. Many of the definitions have been changed, specifically those of *affiliate*, *custodian*, *diagnostic, treatment and care information,* while the definition of *health services providers* information has been removed. Additional disclosure provisions have been added including clarification on disclosure to law enforcement. These changes and others have been incorporated into this updated guide.

This guide has been designed for busy health care professionals. The user will find a comprehensive Table of Contents and a Quick Reference Guide that offers examples of how the Act might apply in some common scenarios. The guide will not provide answers to every situation. We hope that it will give the user enough of a sense of how the Act operates to know when to proceed as usual and when practices may have to be modified. Albertans have always trusted the judgement of their health care professionals. The continued exercise of this good judgement and an understanding of the Act will provide the necessary skills and knowledge for dealing with *health information*.

I wish to acknowledge the individuals who were involved in the revised production of this guide. Roseanne Gallant, Consultant, undertook the writing with editing provided by staff members, LeRoy Brower, Director, Health Information Act, Leahann McElveen, Health Information Portfolio Officer and Brian Hamilton, Health Information Portfolio Officer.

I believe this guide provides a clear understanding and direction of how the *Health Information Act* applies to a person's health records. This Act is so important for the continued confidence of patients as well as the professionals who serve them.

Frank Work,

Information and Privacy Commissioner of Alberta

QUICK REFERENCE GUIDE

Some examples of matters that this guide is intended to address.

AN OVERVIEW

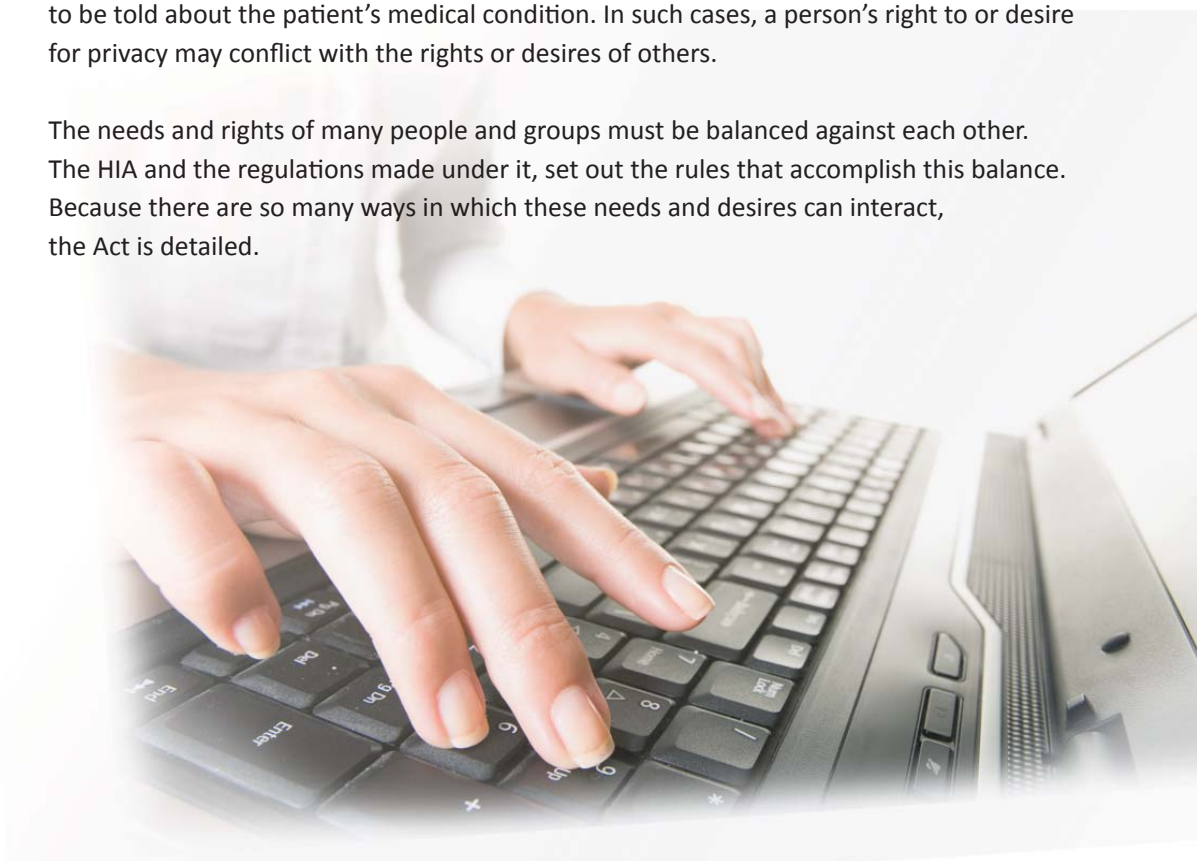
The *Health Information Act* (HIA or the Act) is a detailed piece of legislation for a very simple reason. It deals with complex issues concerning the collection, use, disclosure and protection of *health information* used in the health care system.

Patients are very concerned about what is done with their personal medical information. They want their information closely guarded so that it is not accessed or disclosed against their wishes – either on purpose or inadvertently. No one wants to seek treatment for a sensitive medical problem only to receive a surprise call from someone marketing a product for the treatment of that condition. Similarly, no one wants their neighbour to accidentally discover what medications they are taking or the medical conditions they are being treated for.

Individuals want to feel confident that *health information* stored in electronic *record* systems will be safeguarded and only be used and disclosed appropriately.

At the same time, it's understood that people and organizations providing *health services* need to have access to information to treat people, conduct research and manage the health care system. Other people, such as a patient's family, may have a legitimate reason to be told about the patient's medical condition. In such cases, a person's right to or desire for privacy may conflict with the rights or desires of others.

The needs and rights of many people and groups must be balanced against each other. The HIA and the regulations made under it, set out the rules that accomplish this balance. Because there are so many ways in which these needs and desires can interact, the Act is detailed.



The Act balances the need for privacy and confidentiality against the need for the collection, use and disclosure of information. The introductory section of the Act sets out the purposes of the legislation. The remainder of the Act is divided into parts dealing with:

- a person's right of access, and to request corrections or amendments to their own information;
- general rules for the collection, use and disclosure of *health information*;
- rules for the *Alberta Electronic Health Record*, also known as "Alberta Netcare";
- duties of *custodians* to protect *health information* and their powers under the Act;
- ability of the Minister to designate a *Health Information Repository*;
- creating offences and imposing penalties to deter people from breaching its provisions; and
- methods for reviewing decisions made by *custodians* and resolving complaints.

It is important to note that the Act does not require *health services providers* to abandon everything they have done in practice up to now and start over. While the Act must be followed, professional codes of ethics continue to apply as long as they are not in conflict with the Act. However, if the Act prohibits something, you may not do it, even if your code of ethics would allow it. If the Act is silent on an issue, and your code of ethics either allows or prohibits you from doing a certain thing, you should follow the code of ethics.

DOES THE ACT APPLY TO YOU?

General

In one sense the Act applies to everyone, because it gives people a right of access (subject to certain exceptions) to their own *health information* and prevents others from having access to or obtaining disclosure of that information. People usually do not object to information being shared with their nurse or specialist or someone who is providing a *health service* to them, so long as the sharing of that information is necessary for their treatment.

This Act is primarily concerned with *health information* that is collected and used by individual *health services providers* and organizations in Alberta. The Act defines most of these people and organizations as either ***custodians*** or ***affiliates***. It does not apply to **all** *health information* about an individual or to all types of *health services providers*. Some exceptions are outlined later in this chapter.

We know that access to *health information* is needed to allow people and organizations providing *health services* to treat people, conduct research and manage the health care system. Electronic health *records* are one means to achieve these objectives and the Act recognizes the need to share information among authorized users for authorized purposes while setting out steps to safeguard that information.

Most patients understand that health care is complex and that many people in the health care system need access to their *health information* to provide care and treatment.

Are You a Custodian?

Custodians and *affiliates*, who provide ***health services*** to individuals, are subject to specific rules dealing with *health information*. *Custodians* are, in effect, **gatekeepers** who must be vigilant in determining what information they will collect and share, and with whom they will share it. For example, information may be disclosed to a family member, but this is only possible if the rules governing the *custodian* allow such disclosure.

Custodians and affiliates protect health information

The Act and accompanying regulations define over twenty types of *custodians*. The list includes provincial health boards such as the Health Quality Council of Alberta, a regional health authority such as Alberta Health Services, nursing home operators, licensed pharmacies, and the Minister and Department of Alberta Health and Wellness.

2 DOES THE ACT APPLY TO YOU?

Certain ***health services providers*** become *custodians* through being designated as a *custodian* in the regulation. These *custodians* include physicians, dentists, denturists, dental hygienists, optometrists, opticians, chiropractors, podiatrists, pharmacists, registered nurses and midwives. The Minister of Health and Wellness may also designate other *custodians* through the regulations.

The HIA applies to you if you are a *custodian* who provides a *health service*.

A ***health service*** is a service that is provided to an individual for any of the following purposes:

- protecting, promoting or maintaining physical and mental health;
- preventing illness;
- diagnosing and treating illness;
- rehabilitation; or
- caring for the health needs of the ill, disabled, injured or dying;

but does not include a service excluded by the regulations.

Exceptions

Certain organizations, such as insurance companies, may hold *health information* in their files, however they are not *custodians* or *affiliates* as those terms are defined in the Act, nor does the Act govern the use of *health information* by them.

Other organizations, such as private industry or educational institutions that hold *health information* in their files are also not *custodians* or *affiliates*; however they may employ *health services providers* who are designated *custodians* under the HIA, for example, a registered nurse who is employed by a large oil company to provide *health services* to the organization's employees. Although the organization itself is not a *custodian* under the Act, their employee is and subsequently the *health information* that is collected for the purposes of providing a *health service* is subject to the Act. However, it is important to remember that the HIA does not apply to information that is collected for purposes other than providing *health services*.

Are You an Affiliate?

Under the Act you are an *affiliate* if you are:

- an individual employed by a *custodian*;
- a person who performs a service for a *custodian* as an appointee, volunteer or student;
- a person who performs a service for a *custodian* under a contract or agency relationship with the *custodian*;
- a *health services provider* who is exercising the right to admit and treat patients at a hospital as defined in the Hospitals Act;
- an information manager as defined by the Act; or
- a person who is designated under the regulations to be an *affiliate*.

Custodians are responsible for the actions of their affiliates

Most *custodians* employ individuals to assist them in providing *health services*. *Custodians* may also have contracts with individuals or companies for specific services. Some *custodians* grant privileges to doctors to admit and treat patients in their facilities. Contracted individuals and companies that gain access to *health information* held by *custodians* through employment or contract are examples of affiliates. If these people or companies were not otherwise subject to the Act, they would not be subject to the same *health information* rules of collection, use or disclosure. Consequently, the Act defines them as ***affiliates*** and brings them into the Act. ***It is important for custodians to identify their affiliates because they are responsible for their affiliates actions.***

The Act also provides for *custodians* who may wish to become another *custodian's affiliate*. For example, a group of physicians who practice together in the same clinic may wish to name one of them as the *custodian* to be responsible for HIA compliance on behalf of all the physicians providing *health services* in the clinic. This can be accomplished by asking the Minister of Health and Wellness for such a designation.

Insurance agents, as defined in the *Health Insurance Premiums Act*, are specifically excluded from the definition of *affiliate* and are not subject to the Act nor is a *health information repository* unless it is designated in the regulations as an *affiliate*.

Example 1 DOES THE ACT APPLY?

Sue is a registered nurse employed at a private school. A student tells Sue that he is very depressed and is considering suicide. Sue notes the incident in her files and counsels the student. Sue wants to phone the student's parents.

Is the school a *custodian* and if so, is Sue an *affiliate* of the school?	The school is not a *custodian* under the definition in the Act, so the school is not subject to the Act. Because the school is not a *custodian*, Sue could not be an *affiliate* under the Act despite being employed by the school.
Is Sue a *custodian*?	By referring to the regulations of the Act, regulated members of the College and Association of Registered Nurses of Alberta are designated *custodians*. Therefore, Sue *is* a *custodian*.
Did Sue provide a *health service*?	As Sue is engaged in promoting or protecting the student's mental health and diagnosing or treating his illness, she is providing a *health service*. Sue is a *custodian* who is providing a *health service* and therefore the Act applies. The Act contains a provision that authorizes disclosure of *health information* necessary to avert or minimize imminent harm.

Example 2

DOES THE ACT APPLY?

Jane is a registered nurse employed by an oil company to handle occupational health and safety.

Is Jane a *custodian*?	By referring to the regulations of the Act, regulated members of the College and Association of Registered Nurses of Alberta are designated *custodians*. Therefore, Jane *is* a *custodian*.
Does Jane provide *health services*?	The Act applies to *custodians* and to information relating to *health services* provided by a *custodian*. If a *health service* is not being provided to an individual, the information is not *health information* and the Act does *not* apply.
Is Jane collecting and using information for the purpose of providing a *health service* or to manage personnel?	If Jane is collecting *health information* to process an employment application, she is managing personnel for her employer and the Act does *not* apply. If Jane is providing a *health service* to an employee such as first aid for an injury received while on duty, the Act does apply.
What must Jane consider if the HIA applies?	If the Act applies, Jane will also need to consider the following as it relates to the *health information* she collects: - Collection, use and disclosure rules; - Access and correction rules of *health information*; - Protection of *records* including retention and disposal; - Management of *records*; - Access rules of the Alberta EHR; - When a Privacy Impact Assessment is needed; - Assisting a patient who asks that their *health information* not be used in the Alberta EHR; It is important that Jane consider if the Act applies, and if it does, then all of the factors listed must be considered including the creation of policies and procedures outlining those duties. If the Act does not apply, the information is likely subject to the *Personal Information Protection Act*.

WHAT INFORMATION DOES THE ACT PROTECT?

General

It is important to remember that health care professionals and organizations have always acted as **gatekeepers** of *health information*. They have always gathered information about their patients and used it to provide care and manage the public health care system. They have also protected that information and prevented unauthorized persons from obtaining it. The Act sets out specific rules about how *health information* must be dealt with, but those rules do not radically change what health care professionals have been doing for a long time.

Health Information

The Act protects ***health information*** in the ***custody or control*** of a *custodian* and the Act defines two types of *health information*:

1) *diagnostic, treatment and care information; and*

2) *registration information.*

Custodians have custody of *records* when the *records* are in the possession of the *custodian*. If you have sent the file to storage or the *record* is electronic, but you have the power to retrieve those *records* then they are still under your control.

It is also important to note that the Act deals with *individually identifying* versus *non-identifying* and recorded versus non-recorded information.

This guide focuses largely on *diagnostic, treatment* and *care information*, as it is that type of information that will be involved in most cases when issues arise about collection, use and disclosure (most *diagnostic, treatment and care information* will contain some registration information about the individual who received a *health service*).

Diagnostic, Treatment and Care Information

This type of information is what health care professionals deal with on a routine basis. It includes information about:

- a person's physical or mental health;
- the treatment they are receiving or have received including information about *health services providers* involved in their care;
- drugs they have been provided with;
- health care aids or products they have received;
- the amount of health care benefits paid or payable for services provided to them; and
- donation of a body part or substance and information derived from it.

Registration Information

This type of information includes:

- demographic information (name, signature, gender, photograph, *personal health care number*, etc.);
- location, residency and telecommunications information (mailing and electronic addresses, past residences, citizenship/ immigration status);
- *health service* eligibility information; and
- billing information.

Personal Health Numbers (PHN) receive particular attention. Only *custodians* and persons designated under the regulations may require an individual to provide their *personal health number*. The list of persons designated in the regulations include:

- ambulance attendants and operators;
- the Workers' Compensation Board; and
- persons other than *custodians* who provide *health services* and need the number to seek reimbursement from the Alberta Health Care Insurance Plan, for example, massage therapists.

Organizations such as minor sports associations and daycares cannot require collection of a PHN.

When asking for a *personal health number*, *custodians* and those authorized by regulation must advise the individual of their authority to ask for the number. If someone without authority requests a *personal health number*, an individual can refuse to provide the number.

Recorded vs. Unrecorded Information

Information is not *health information* unless it is contained in a ***record***. The Act contains a broad definition of what constitutes a ***record***. A *record* includes such things as x-rays, notes, letters, audio-visual recordings and lab reports. A *record* also includes any other information recorded or stored in any manner, meaning the health *record* can be stored in paper format or electronically in any electronic health *record* system.

Custodians are often told things that may not get written down in a ***record***. Technically, **unrecorded** information is not *health information*. Nevertheless, it is protected by the Act and may only be used or disclosed for the purpose for which it was provided.

Unrecorded information is protected by the Act

Example 3 — CONFIDENTIALITY OF UNRECORDED INFORMATION

Bill sees the nurse practitioner in his doctor's office four times a week for the management of his high blood pressure. Bill often looks a little worse for wear and comments that he has been doing a lot of partying lately. The nurse practitioner makes no note of it in Bill's chart, as it has no bearing on Bill's treatment. The nurse practitioner also treats Bill's twin brother who comments that he is worried about Bill's drinking.

Can the nurse practitioner discuss Bill's disclosure with his brother?

Is what Bill said *health information*?

As the information was not put into a *record*, it is not *health information*.

Nevertheless, the Act provides that such unrecorded information can only be used for the reason it was provided.

It is difficult to pinpoint exactly why Bill disclosed the fact he had been doing a lot of partying. However, we can be fairly certain he did not disclose it for the purpose of having it discussed with others. Consequently, the information cannot be disclosed even though no *record* was made of it.

Individually Identifying vs. Non-Identifying Information

The Act is primarily concerned with the protection of ***individually identifying health information***. Not all of the information used in the health care system needs to be attached to the name of a specific patient or to a patient's *personal health number*. It may suffice, particularly in the area of research, to collect, use and disclose *health information* without identifying the individual from whom it came. If an individual cannot be identified readily by the information disclosed, their privacy is much less likely to be infringed. It is therefore important to assess the context of the collection, use and/or disclosure to ensure the information does not identify an individual.

Because of this, the Act allows *non-identifying health information* to be collected and used for any purpose. It may also be disclosed for any purpose, other than specific restrictions for use in data matching.

Example 4

IDENTIFYING VS. NON-IDENTIFYING HEALTH INFORMATION

A researcher has asked a physician working in a small town for de-identified *health information* about patients with a rare medical condition.

What is the likelihood that patients could be identified?	It is possible that this seemingly anonymous revelation could identify individual patients. As the physician works in a small town and the condition under research is rare it may be quite easy to identify the individual with such a condition. In a large city, such a disclosure might not identify individual patients.
Would this be a disclosure of identifiable *health information?*	It is important to assess the context of the disclosure to ensure the information does not identify an individual.

DUTIES AND POWERS OF CUSTODIANS & AFFILIATES

Relationship Between Custodians and Affiliates

Much of the time *custodians* are assisted by their *affiliates*. When you need to see a doctor you first make an appointment. When you arrive for your appointment someone will collect information from you. Individuals employed by the *custodian* to help them provide *health services* are *affiliates*.

Custodians **are responsible for the actions of their** ***affiliates***. When *affiliates* collect, use or disclose information, they do so on behalf of *custodians*. When patients provide information to *affiliates*, it is as if they had given the information directly to the *custodian*. If an *affiliate* does something the Act forbids them to do, it is as if the *custodian* did it.

Affiliates must comply with the Act and regulations, as well as with the policies and procedures adopted by the *custodian*.

Establishing Policies and Procedures

Custodians must establish **written** policies and procedures that they will use in implementing the Act and regulations. An example of this would be a policy that forbids employees *(affiliates)* from accessing patient *records* unless they are directly involved with the patient's care. *Custodians* who are members of regulated health professional bodies may reference their profession's standards of practice to assist them in this duty.

A copy of these policies must be given to the Minister of Alberta Health and Wellness if requested. In addition, the *Office of the Information and Privacy Commissioner* (OIPC) may ask to review policies when conducting investigations, and policies are required attachments in a Privacy Impact Assessment submission to the OIPC.

The Prime Directive

It is important to understand that *custodians* can only collect, use or disclose the amount of *health information* **essential** to carrying out the purpose for which the information was provided in the first place. In other words, ***custodians* must collect, use and disclose the least amount of information necessary and preserve the highest degree of patient anonymity possible to carry out the intended purpose**.

Individuals can also expressly ask a *custodian* to limit disclosure of their *health information* and these wishes must be considered when disclosure is contemplated. How this can be accomplished with electronic health *records* is discussed later in this guide under the section of the Alberta EHR.

If *health information* is collected, used or disclosed for a purpose other than providing a *health service* or determining eligibility to receive a *health service*, *custodians* must not only comply with the **prime directive**, they must first consider whether aggregate *health information* is adequate for the intended purpose. The Act requires *custodians* to collect, use or disclose aggregate *health information* unless that level is insufficient for their purpose.

Ensuring the Accuracy of Information

Custodians must make a reasonable effort to ensure that *health information* in their **custody or control is accurate and complete** before using or disclosing that information. You are not expected to be perfect, but you must take steps that a reasonable, capable *custodian* would take. If a diagnosis has changed, some note about that on earlier records may avoid having another provider act on an inaccurate diagnosis in the future.

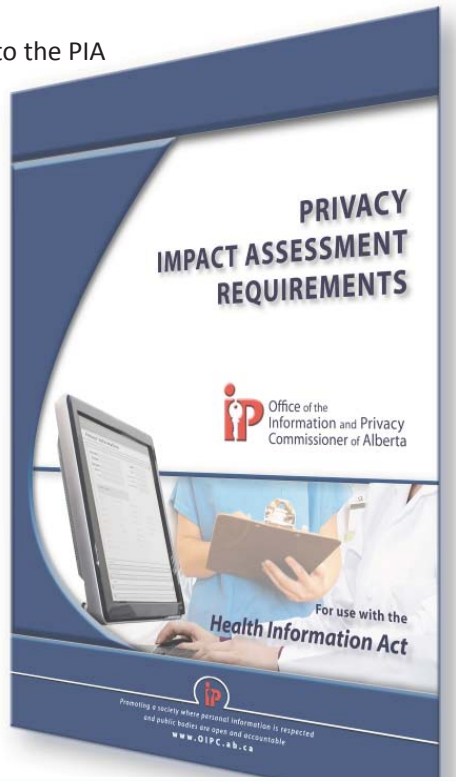
Privacy Impact Assessments

If a *custodian* wants to change or implement new business practices or information systems involving *health information*, it must prepare a Privacy Impact Assessment (PIA). The assessment must describe how those changes or new initiatives will affect privacy and it must be submitted to the *Commissioner* before the changes or new initiatives are implemented. For example, a plan to increase collection of patient information or moving from paper to electronic patient files would both be reason enough to complete a PIA.

Privacy Impact Assessments demonstrate that the *custodian* has considered the privacy risks of the system or practice and has taken reasonable steps to mitigate against those risks. New practices and technologies can evolve after projects are implemented. New threats to privacy may also develop over time. It is recommended that you review your PIA(s) periodically to ensure any risks caused by these changes are mitigated. If there are changes to your PIA, it may be necessary to submit a PIA amendment to the *Commissioner*.

To assist *custodians* in submission of Privacy Impact Assessments, the *Office of the Information and Privacy Commissioner* has outlined what must be included in a submission:

- **Cover Letter** signed by the *custodian*
- **Cover Page** providing contact information related to the PIA
- **Section A** - Project summary
- **Section B** - Organizational privacy management
- **Section C** - Project privacy analysis
- **Section D** - Project privacy risks and mitigation plans
- **Section E** – Privacy and security policy and procedure attachments



Detailed PIA Requirements are available at www.**OIPC**.ab.ca or through the Queen's Printer.

Information Manager Agreements

Custodians have the ability to enter into an agreement with an *information manager* to provide a number of *health information* management and/or technology services. *Information managers* are considered *affiliates* of a *custodian*. *Health information* may be provided to *information managers* **without consent** of the individual for the purposes authorized by the agreement.

The act defines the term **"*information manager*"** to mean a person or body that:

- processes, stores, retrieves or disposes of *health information*;
- strips, encodes or otherwise transforms *individually identifying health information* to create *non-identifying health information*, in accordance with the regulations; or
- provides information management or information technology services.

Custodians who require information managers **must** enter into a written agreement that covers:

- services to be provided by the *information manager*;
- all requirements specifically listed in the regulations; and
- that the *information manager* must comply with the Act, the regulations and the agreement with the *custodian*.

Custodians may serve as *information managers* to other *custodians*. For example, Alberta Health and Wellness serves as the *information manager* to all participating *custodians* in the *Alberta EHR*.

Custodians who enter into an agreement with an out-of-province *information manager* must ensure that the agreement contains specific privacy and security safeguards as outlined in the regulations.

General

Both the Act and the regulations require *custodians* to protect *health information* in their **custody** or under their **control**. The Act provides specific requirements for protecting electronic health *records*. Information that is to be stored or used outside of Alberta or disclosed to a person outside of Alberta must also be protected. This means that you must protect information, not only while it is in your hands, but when you put it in the hands of other people. This will be done by agreement, as outlined in the regulations, but an agreement is not required if the disclosure is for the sole purpose of providing continuing care and treatment to the patient.

Reasonable steps must be taken

Custodians must take **reasonable steps** to maintain **administrative, technical and physical safeguards** to protect *health information*. Reasonable steps are those that a careful *custodian* would take.

These safeguards are meant to:

- protect both **the confidentiality of the information** and the **privacy of the individuals** who are the subjects of that information. For example, files should not be left unattended in an area to which the public has access. Nor should people picking up prescriptions be put in the awkward position of having to discuss their medications in front of others;
- protect against **reasonably anticipated** threats or hazards to the security or integrity of *health information* or the loss, unauthorized access, use, disclosure or modification of *health information*;
- address the risks associated with electronic health *records*; and
- ensure *custodians* and *affiliates* comply with the Act.

You **Must** do the Following:

- Identify and record administrative, technical and physical safeguards for *health information*;
- Implement and periodically assess *health information* safeguards;
- Designate an *affiliate* who is responsible for the overall security and protection of *health information*;
- Enter into agreements with persons/groups to maintain the confidentiality and privacy of *health information* that is to be used or stored outside of the province;
    - The regulations contain specific requirements regarding the contents of such an agreement so that the *custodian* can ensure the person receiving the *health information* properly protects it. An agreement to protect *health information* given to them is a contract that can be enforced wherever they are located; and
    - An agreement is not necessary if the information is disclosed for continuing care and treatment.
- Ensure that your *affiliates* know what the safeguards are and that they follow them; and
- Create sanctions for *affiliates* who breach or attempt to breach the safeguards created for *health information*. This is not meant to frighten people, but to impress upon *affiliates* the importance of preserving privacy and confidentiality. For example, employees should be required to sign an oath of confidentiality and if found in violation of the oath, they would be subject to disciplinary action or dismissal.

Custodians have obligations

Physical Safeguards

- Keep white boards containing patient information away from public areas;
- Physically secure the areas in which *health information* is stored using measures such as:
    - Locked buildings or rooms;
    - Restrict access to server and keep it in a locked room;
    - Lock filing cabinets and unattended storage areas;
    - Alarm system and consider need for security guards;
    - Restrict access to *records*/storage areas to authorized personnel and consider use of access cards; and
    - Cable locks to secure laptops.
- Position computer terminals and fax machines so they cannot be seen or accessed by unauthorized users;
- Clean desk policy; and
- Lock shredding bins for disposal of sensitive *records*.

Technical safeguards

- Implement access controls to ensure *affiliates* only gain access to the *health information* needed to do their jobs;
- Ensure each system user has a unique username;
- Implement a strong password policy to ensure passwords cannot be guessed easily and change passwords regularly;
- Maintain system audit trails that show who has viewed and modified *health information*;
- Review system audit logs to detect and investigate unauthorized activity;
- Use password protected screensavers and security screens so visitors cannot view terminals;
- Install and monitor anti-virus systems, firewalls and in larger networks, intrusion detection systems;
- Implement change controls and test procedures to prevent system maintenance and upgrades from adversely affecting data integrity or availability;
- Implement a layered defence on mobile devices such as;
    - passwords;
    - software/hardware to lock hard drives; and
    - properly implemented encryption.
- Implement document-tracking systems so that you know when a document is removed, who has it and when it was returned;
- Implement data integrity controls;

- Use encryption for data storage and transmission over public networks;
- Encrypt sensitive e-mails;
- Implement controls to protect wireless networks from eavesdropping; and
- Implement and regularly test data backup and business recovery plans.

Administrative Safeguards

- Implement policies and procedures;
- Train staff so they know what your policies and procedures are, the importance of following those policies and the impacts that might follow a breach (someone could be fined, disciplined or fired);
- Perform a risk assessment and establish appropriate safeguards;
- Consider implementation of security checks to screen key employee positions;
- Have employees take an oath of confidentiality;
- Utilize the most secure method of sharing *health information* such as the Alberta EHR versus fax or unencrypted e-mail;
- Control the types of information that may be sent by fax or e-mail;
    - Use preprogrammed addresses and phone numbers on faxes and e-mails that are regularly sent to certain places. This minimizes keystroke errors that might result in information being misdirected; and
    - Regularly confirm that such addresses and phone numbers have not changed.
- Periodically assess effectiveness of the policies and procedures and safeguards.

Staff training enhances respect for patient information

Example 5	**ADMINISTRATIVE CONTROLS**
Jill works as a pharmacist for a large pharmacy chain. In the prescription line, a customer overhears Jill discussing a prescription with another customer.	
What administrative controls are required?	The privacy training program offered by Jill's pharmacy chain should have made it clear that she should not discuss prescriptions with a patient in a way that others can overhear. The pharmacy chain should implement policies and procedures which guide *affiliates* on reasonable steps to take to prevent those waiting in line from overhearing conversations between the pharmacist and patients.

Restrict Access by Staff

Remember that *affiliates* must only collect, use and disclose *health information* in accordance with their duties to the *custodian*. This concept is also known as the "need to know" principle. *Custodians* that employ many people will likely have *affiliates* who have no need to access *health information.* Some *affiliates* will only need access to limited information.

Diagnostic, treatment and care information should only be seen by those with a need to know, for instance:

- Administrators dealing with billing likely do not need to see detailed treatment information;
- Administrative support staff whose role is to book appointments and answer general inquiries from patients do not need to see detailed treatment information; and
- Doctors and nurses only need to see files of people with whom they are directly involved.

Example 6	**NEED TO KNOW**
A patient with a history of drug abuse is admitted for an emergency appendectomy. A file is obtained from her doctor that contains a detailed history of her treatments over the past few years. **During night shift, a nurse not involved in her care browses through the file.**	
Is this wrong?	Access to such files should be restricted to persons treating the patient. *Custodians* should have a clear policy about this and staff should be trained accordingly. *Custodians* must create sanctions to encourage *affiliates* to follow the rules and should regularly check that the rules are being followed.

Example 7 NEED TO KNOW: ELECTRONIC RECORDS

During divorce proceedings, an individual alleges that his wife accessed his *health information* through her friend who works at the clinic where his doctor practices. He alleges that his wife accessed and printed a list of his medications from the clinic's electronic health *record* system, which were subsequently used in court proceedings.

How should the *custodian* enforce the need to know principle with his *affiliate*?

The physician should review the access logs of the electronic medical *record* system, which may find an access that does not match up with treatment events provided to the individual.

The physician must determine whether the access to the individual's *health information* was for the purpose of providing diagnostic, treatment or care, or for any other authorized purpose under the Act.

The physician, as a *custodian*, is required to have policies and procedures addressing collection, use and disclosure of *health information,* including safeguarding that information and *affiliates* should be trained accordingly.

In this case, the physician decides to discipline his *affiliate* as well as send her for remedial privacy training.

Access and use of *health information* for personal reasons may constitute an offence under the HIA, and the *affiliate* may be subject to a fine.

Retention and Disposal of Records

The safeguards that are created to protect *health information* must also address retention of *health information* and include appropriate measures for the proper disposal of that information when those time frames expire.

Custodians are advised to follow the ten year retention period provided for in the Act with regard to use and disclosure logs, as well as any professional college guidelines regarding retention and disposal of *records*.

When you move, files should not be left behind or tossed in a garbage bin accessible to anyone who wanders by. The most appropriate method for disposal of paper *health information* is by shredding. Use professional disk wiping software to remove *health information* from computer hard drives and other media. Alternatively, destroy the media.

COLLECTING HEALTH INFORMATION

General

The rules in the Act about collecting *health information* only apply to information collected when a *custodian* is subject to the Act.

Remember the prime directive

Custodians must only collect *health information* in accordance with the Act. Even if another Act authorizes them to collect *health information*, the HIA still governs how they collect it and from whom they collect it. *Affiliates* must only collect *health information* in accordance with their duties to the *custodian,* as the information they collect is collected on behalf of the *custodian*.

The Act authorizes *custodians* to collect information for certain purposes only. There are five limits to collection:

- Collect only essential information;
- Collect with highest degree of anonymity;
- Collect in a limited manner;
- Identify authority to collect individually identifying information; and
- Collect directly from the individual unless indirect collection is authorized.

Remember the prime directive. You must only collect as much *health information* as is essential to carry out the purpose for which the information is being collected. In addition, the information collected must relate directly to the purpose of collection. *Custodians* should have a policy about what *health information* they routinely collect and who is allowed to collect it to ensure they are not breaching these rules.

Remember that *health information* can be *individually identifying* or *non-identifying*. *Custodians* may collect *non-identifying health information* for any purpose.

Example 8	NECESSITY AND PURPOSE IN COLLECTION
Doctor Ferguson has developed a theory about the connection between blood type and a certain ailment. He plans to do research in this area and is in the process of preparing a research proposal. In anticipation of this, he routinely asks new patients for their blood type when they first come to see him.	
Is this a proper collection of information?	The prime directive requires that *custodians* collect only the amount of information essential to allow them to carry out the purpose for which the information is provided. The Act also only authorizes collection of information that is directly related to that purpose, so for patients coming to Dr. Ferguson with a sore throat, blood type is likely irrelevant. It is improper to routinely collect such information when it is not needed or directly related to providing the *health service* the patient was seeking. Dr. Ferguson could only collect this information in this manner if he had first obtained *Research Ethics Board* (REB) approval. A recognized REB would need to consider this activity and weigh the public interest in the proposed research against the public interest in protecting privacy, and decide whether consent of the individuals is required.

Collection of Individually Identifying Health Information

Health information that is *individually identifying* is simply information that will identify the person whom the information is about. The Act allows *custodians* to collect such information for a number of purposes. The two most common reasons are:

1) for the purpose of providing a *health service*; or

2) determining or verifying eligibility to receive a *health service*.

Other authorized purposes for collection of *individually identifying health information* include:

- conducting investigations;
- holding discipline proceedings;
- educating *health services providers*; and
- conducting research approved by a *research ethics board*.

Custodians may also collect *individually identifying health information* if the collection is authorized by an enactment of Alberta or Canada. For example, the reporting of a communicable disease is authorized under the *Public Health Act.*

An individual can refuse to provide their PHN to a person who does not have authority to require it

Collection of Personal Health Numbers

Only *custodians* or persons designated by the regulations for specific purposes have the right to require someone's *personal health number* (PHN). Persons designated by the regulations include insurers and the Workers' Compensation Board (for the purpose of handling claims) and a number of provincial government bodies (to administer various benefits programs). Organizations such as minor sports associations or charitable service organizations do not have authority to require collection of a PHN.

Collecting Directly from the Individual Concerned

A *custodian* **must** *collect individually identifying health information* directly from the person it concerns unless the Act authorizes collection from a third party.

If you collect information directly from the person it concerns you must take **reasonable steps** to inform the person of:

Openness avoids misunderstandings

- the purpose for which the information is collected;
- the *custodian's* specific legal authority for collecting the information; and
- the title and business address and phone number of an *affiliate* who can answer questions about the collection.

The Act says this information should be given **when** collection takes place. Ideally, it should take place before questions are asked or forms filled in so that the patient has time to think about what is being asked for. If a patient wants to authorize a *custodian* to collect information from someone else, or to express their wishes about whom disclosures may be made to, such matters can be dealt with at the same time.

Custodians should be very clear about their reasons for collecting information. If people are told why certain information is required, what it will be used for and who will have access to it, they generally will not be surprised or annoyed by subsequent uses or disclosures for those purposes. This is particularly true as the Act allows *custodians* to share information for the purpose of providing *health services* **without the individual's consent**.

Health service is a broadly defined term. All the people who might provide a *health service* may not be readily apparent to a patient. It is unnecessary to provide an exhaustive list, but generally informing patients who may see their information and what steps have been taken to protect their information may avert questions at a later time. For example, physicians and nurses are obvious recipients of *health information*, whereas students, researchers or peer reviewers are not as obvious recipients of *health information*.

The Act does not specify how this notice of collection is to be given to the patient. *Custodians* must take **reasonable steps**. Again, what is reasonable requires the exercise of good judgement and common sense. The use of brochures, notices, signs and oral explanations are some suggested methods. *Custodians* should be sure that signs and notices are obvious and drawn to their patients' attention. Fine print at the bottom of a lengthy form is not acceptable.

Collecting from a Third Party

In certain circumstances the Act allows *custodians* to collect *individually identifying health information* from someone other than the person seeking *health services*.
Allowable circumstances are:

*Information does not **always** have to be collected directly from patients*

- Where the individual **authorizes** collection from someone else;

  When a patient authorizes collection from someone else, the patient should still be informed what information is to be collected, from whom, and the purposes for which it will be used. While strictly speaking the Act does not require this, it would avoid arguments later on about exactly what the patient authorized the *custodian* to do. It may be advisable to obtain a written authorization.

- Where the individual is **unable** to provide the information and the *custodian* collects it from an authorized representative such as a trustee or guardian of a person under the age of 18, or an agent under a personal directive;

  Collecting from children raises difficult issues. Persons under the age of 18 that are capable of making their own medical choices must be allowed to do so. *Custodians* cannot use this provision to consult the parents of a 16-year-old if the young adult is perfectly capable of providing the needed information. However, other provisions in the Act might allow a *custodian* to consult a third party such as a parent.

- Where the *custodian* believes, on **reasonable grounds**, that direct collection would **prejudice**;
    - the interests of the individual;
    - the purpose of the collection;
    - the safety of another individual; or
    - that would result in the collection of inaccurate information.

    In certain situations information may be gathered from someone other than the patient;
        - A drug addict may give false information in an effort to obtain drugs and confronting such an individual may provoke a violent response; or
        - A person with advancing dementia or other cognitive impairment may not be able to give accurate information.

    This rule allows *custodians* to go to other sources to ensure that accurate information is obtained and dangerous situations are avoided.

- Where direct collection is **not reasonably practicable**;
    - An unconscious or confused patient may not be able to give information;
    - In an emergency there may not be time to question the patient; or
    - A patient may not know the answer to a question but a third party, such as a family member, might.

- Where the information is available to the public;

- Where the information is collected to assemble a family/genetic history, determine/verify eligibility, or inform a Public Trustee or Public Guardian; and

- Where the information is collected from a third party in a situation where the Act would allow disclosure of that information to the third party. For example, the Act allows a specialist to collect information from a patient's family practitioner without consent.

Example 9

COLLECTING INFORMATION FROM A PATIENT'S FAMILY

Mary is a senior citizen who is an insulin dependant diabetic. Mary lives on her own and suffers from short term memory loss as a result of a recent stroke. Mary has been receiving routine care from her family physician, Dr. Brown. The doctor has noted that Mary's blood sugars are not controlled and her foot care regime has diminished since the stroke. Dr. Brown suspects that Mary is forgetting to take her insulin and perform her routine blood sugar testing.

Can Dr. Brown collect Mary's *health information* from other sources?

Mary could be asked to authorize collection of her *health information* from someone else if Dr. Brown considers her competent to execute such an authorization.

Dr. Brown could collect information from someone else on the basis that it was not practicable to obtain the information from Mary, as Mary believes that she has been diligently following her routine care schedule.

Dr. Brown could collect information from someone else on the basis that collecting from Mary may result in the collection of inaccurate information.

Information collected from a third party may not be as accurate or reliable as that collected directly from the individual it concerns. **Remember that you have a duty to take reasonable steps to ensure the information is accurate and complete**. It may be appropriate to verify such information with the patient at a later time if that is possible and justifiable.

Confidentiality of information collected from a third party cannot necessarily be guaranteed. However, *custodians* have the authority to maintain the confidentiality of third party information that was supplied in confidence. For example, a *custodian* may refuse to release information that would lead to the identification of the third party where the information was supplied in confidence.

Unsolicited Information as Collection

Collect also means to **receive** *health information*. *Health information* volunteered by someone such as a family member or friend is information collected by the *custodian,* even though the *custodian* did not actively solicit it. *Health information* received electronically, for example, lab results or text reports, is also information that a *custodian* has collected.

Collecting also means receiving

It would be good practice to note the source of such information when it is received, particularly if it will be used as a basis for treatment. Remember that *custodians* must make a reasonable effort to ensure that information is accurate and complete before they use or disclose it.

Example 10 **RECEIVING UNSOLICITED INFORMATION**

During a consultation, Dr. Jones' patient, John, tells her that he believes his neighbour, Sue, beats her children. John says he regularly sees the children with extensive bruising to their faces. Sue and her children are also patients of Dr. Jones.

Is this unsolicited information a collection under the *Health Information Act*?	Yes, if the information is recorded. Although the information was volunteered and not requested by Dr. Jones, it still qualifies as a collection as defined by the Act.

Collection using a Recording Device or Camera

If you collect *health information* from an individual by using a recording device, camera or any other device **that may not be obvious to the individual**, you must obtain the individual's **written consent** before collecting the information.

USING HEALTH INFORMATION

General

Use of information is restricted to prescribed purposes

Use as defined in the Act means to apply *health information* for a purpose and allows *health information* to be reproduced as it is being used. The concept of use also includes appropriate and controlled access to and sharing of *health information*. Providing shared access to *health information* through the Alberta Electronic Health Record (EHR) is also a use. The Alberta EHR is discussed later in this guide.

Disclosure and use are two distinct things. Disclosure is discussed later in this guide. If one *custodian* provides *health information* to someone outside his or her organization, that is a disclosure of the information.

Custodians may only use *health information* in accordance with the Act. *Custodians* cannot use *health information* for marketing purposes or for soliciting donations without consent.

Affiliates may only use *health information* in accordance with their duties to the *custodian*. **Remember the "need to know" principle**. An *affiliate* who is responsible for a patient's care should not be giving information about that patient to another *affiliate* who is not involved in the care of that patient. As with collection, there are limits to using individually identifying *health information*.

Remember the prime directive. You must use only the amount of *health information* essential to carry out the authorized purposes for which the information was provided and at the highest level of anonymity.

Use of Health Information

Use implies access and sharing of information among *custodians* and *affiliates* within an organization. The Act allows *custodians* to use *individually identifying health information* for a number of authorized purposes. It also means that *affiliates* of a *custodian* may access *health information* required to perform duties related to any of the authorized uses without an individual's consent.

The two most common uses are:

- for providing a *health service*; or
- determining or verifying a person's eligibility to receive a *health service*.

Other uses include:

- conducting investigations;
- discipline proceedings, practice reviews and inspections;
- conducting research (research proposals must undergo a research ethics review);
- educating *health services providers*; and
- managing internal operations.

The Minister and Department of Alberta Health and Wellness, provincial health boards, (e.g. Health Quality Council of Alberta) and Alberta Health Services are permitted four additional uses under HIA. These uses are to:

- plan & allocate regional resources;
- manage the health system;
- conduct public health surveillance; and
- develop health policies and programs.

Remember, persons, other than *custodians*, authorized in the Regulation to collect *personal health number* (PHN), for example, insurers, the Workers' Compensation Board and some provincial government bodies, may only use a PHN for the purpose for which it was provided.

Accuracy and Completeness

Custodians must take **reasonable steps** to ensure that information is accurate and complete before they use it. In most instances, **reasonable** would include assessing whether the information is:

- accurate;
- up to date;
- complete;
- relevant; and
- not misleading.

Reasonableness may depend upon the circumstances. You should be careful if you collected the information from a third party or if the patient gave you the information directly, but seemed confused or unsure.

What is reasonable may also depend on what the information is to be used for and its impact on the patient. Knowing someone's date of birth is obviously less important than knowing whether they have an allergy to an anaesthetic when they arrive unconscious and require emergency surgery. The Act does not change existing practice. *Custodians* should already be well aware what constitutes a **reasonable effort**.

DISCLOSING HEALTH INFORMATION TO THIRD PARTIES

General

Custodians may need to disclose

The word "disclose" is not defined in the Act. However, **disclosure** occurs when a *custodian* provides *health information* to another *custodian* or to other entities. It is important to note that making *health information* accessible to the provincial EHR is considered a use, not a disclosure.

Remember that the Act applies to the disclosure of all *health information*, whether it was collected before or after the Act came into force.

Disclosure must be distinguished from an **access** request. A request for access to *health information* means a request by an individual who wants to see or obtain a copy of their own health *records*. The Act sets out a procedure for making such requests. Generally, other parties have no right to make such a request. Access requests are discussed in a subsequent section of this guide.

There are two circumstances in which *custodians* may need to disclose *health information*. They may:

- have to disclose (mandatory disclosure); or
- decide to disclose (discretionary disclosure).

In some cases, *custodians* have no choice but to disclose information because the law requires disclosure. In other cases, they may decide to disclose information, even against the patient's wishes or without the patient's permission, so they can protect others or do what is best for the patient.

An individual's consent is required before *health information* is disclosed unless provisions of the Act authorize disclosure without consent. **Remember** that *custodians* are responsible for the actions of their *affiliates*. *Custodians* must only disclose information when the Act allows them to in the manner set out in the Act. *Affiliates* must only disclose information in accordance with their duties to the *custodian*. *Affiliates* should not be disclosing information to other parties without authorization.

Remember also that information can be *identifying or non-identifying*. It is the disclosure of *individually identifying health information* that is restricted by the Act.

Consent to Disclosure

The **general rule** is that *custodians* may disclose *individually identifying health information* to the person who is **the subject of the information or to persons acting on that subject's behalf**. The latter group was discussed in the section on collecting *health information* and includes people listed as guardians (such as parents) and personal representatives. Disclosure to other parties is made only in the specific circumstances set out in the Act.

Obtaining consent avoids problems

Particular care must be taken when dealing with **persons under the age of 18 years**. If a person under the age of 18 understands the nature of the rights and powers set up by the Act and the consequences of exercising those rights and powers, *custodians* must treat that person as they would treat any other competent person.

If a person does not have the **mental capacity** to consent to disclosure, *custodians* may disclose information about that person without consent if it is in that person's best interest.

Of course, even where the Act does not specifically provide for disclosure to a third party, *custodians* may disclose information to a third party if the patient **consents** to that disclosure. The Act is very specific about the **form of the consent**.

The **consent** must be given **electronically or in writing**. A consent authorizing a *custodian* to disclose information must specify or contain:

- the information to be disclosed;
- the purpose for which the information may be disclosed;
- the identification of the person receiving the information;
- an acknowledgement that the person providing the consent is aware of the reasons why the information is needed and the risks and benefits of either consenting or refusing to consent;
- the effective date of the consent and the expiry date (if any); and
- a statement advising the person that they may revoke the consent at any time.

Any disclosure that takes place, including for research, must be in accordance with the consent given and in the form described above.

Example 11	CONSENT
Judy is being discharged from a psychiatric facility back to her group home. The psychiatric facility wishes to inform the group home leader of Judy's release and discharge plan.	
Is this disclosure allowed by the Act and is consent required?	*Custodians* may disclose *health information*, without consent, for the purpose of providing continuing care and treatment to the patient. Disclosure should be limited to only what is necessary to meet the purpose. In this example, if it is determined that the group home leader is a continuing care provider, then disclosure would be allowed without consent.

Example 12	CONSENT
Grace has suffered a back injury and has applied for short term disability benefits. Her insurance company has asked her physician, Dr. Smith, to disclose *health information* for the purpose of assessing her insurance claim.	
Is consent required?	Unless the Act provides for disclosure without consent, a properly executed consent form, as prescribed above, is always required. There is no provision in the Act for disclosure to insurance companies without consent. If the insurance company supplies a consent form with their request, Dr. Smith will need to assess the consent form to ensure it adheres to the requirements of the Act and if so, may disclose *health information* to the insurance company which is limited to the purpose outlined in the consent form.

You rarely have to disclose

Duties and Discretion of Custodians

Custodians **do not have to disclose** *health information* except in a very few cases. Most of the rules in the Act say that a *custodian* **may** disclose information in certain situations. This means the *custodian* has the **discretion** to refuse disclosure, even though disclosure may be authorized. Therefore, professional **codes of ethics still apply**. Even if the Act allows disclosure, you should not disclose information if your code of ethics forbids disclosure.

Custodians must be sure the disclosure is made to the **correct party**. The Act requires that *custodians* make a **reasonable effort** to ensure that disclosure is made to the person authorized and intended to receive the information. Safeguards were discussed earlier in this guide in the section on protecting *health information*. For example, if you are sending information to Dr. Anderson and there are four Dr. Andersons, you have a duty to ensure the correct doctor receives the information or that lab results are not faxed to the wrong person.

How Much to Disclose

Remember the prime directive. *Custodians* must only disclose information that is **essential** to allow the *custodian* or recipient to carry out the purpose for which the information is being disclosed. When a patient consents to provide *health information* in support of a back claim to an insurance company, it would be inappropriate to send the insurance company the patient's complete medical chart going back twenty years, especially if the information is not all related to the back problem.

Disclose only essential information

Any **expressed wishes by** the person must be considered. *Custodians* must consider those wishes, and any other relevant factors, when they decide how much *health information* to disclose.

Notice to the Recipient of the Disclosure

If a *custodian* discloses *individually identifying diagnostic treatment and care information*, without consent, the *custodian* must inform the recipient **in writing** of the purpose of the disclosure and the authority under which the disclosure is made.

This does not have to be done if the disclosure is to the patient themselves or to another *custodian* for the purpose of providing a *health service*, or to the police. However, in many of the examples which follow later in this chapter, notice would have to be given.

Notation of Disclosures

If a *custodian* discloses a *record* that contains *individually identifying diagnostic, treatment and care information*, without consent, the *custodian* must log that disclosure. The log must contain:

- the name of the person to whom the information was disclosed;
- the date and purpose of the disclosure; and
- a description of the information disclosed.

The requirement to make a note does not apply to *custodians* that permit other *custodians* electronic access when the electronic system automatically keeps an electronic log of the information listed above.

The notation or electronic log must be retained for ten years and the person who is the subject of the information may seek access to and request a copy of the information.

This section simply allows a patient to see which, if any, *records* have been disclosed and, if they have been disclosed, to whom they were disclosed. Remember that *record* has a specific meaning under the Act.

You Have to Disclose Certain Information

The Act itself does not require disclosure, but it allows disclosure so that *custodians* can comply with other legislation or court orders that do require disclosure.

Four examples are:

- The *Public Health Act* requires disclosure about people who have or may have a notifiable infectious disease;
- The *Cancer Programs Act* requires disclosure of "reportable cancers";
- The *Gunshot and Stab Wound Mandatory Disclosure Act* requires disclosure from health care facilities or emergency medical technicians who treat gunshot or stab wounds. An example for this provision can be found later in the guide under disclosure to police; and
- The *Child, Youth and Family Enhancement Act* requires disclosure about children who may be victims of suspected child abuse.

In court cases involving insurance claims or personal injury claims, the parties to the action may have to disclose medical information. In most cases this is done with consent. However, the court will issue an order or subpoena to compel disclosure if that is necessary. The Act allows *custodians* to comply with such orders as long as they are issued from courts with jurisdiction in Alberta or Canada.

Remember that you still need to be careful about what information you disclose. The duty to disclose only the information that is **essential** for the purpose for which it is being disclosed may still govern where a court order is not very specific about precisely what is to be disclosed.

You Decide to or are Asked to Disclose Without Consent

The Act recognizes the fact that disclosure without consent **may** be necessary in a number of cases. This guide covers only disclosures that are likely to occur regularly. Usually these are cases that contribute to the efficient running of the health care system or cases where other interests that will be protected by disclosure are more important than the patient's privacy interest.

Parents don't have an automatic right to children's information

It is important to note that the Act makes no specific provision for the disclosure of information to the parents of children. Disclosure is only allowed, even to parents, if one of the following grounds for disclosure exists, or if the child is too young to understand the nature of the rights and powers created by the Act and the consequences of exercising those rights and powers.

Disclosure to Other Custodians

Diagnostic, treatment and care information is regularly shared between *custodians*. The health care system would grind to a halt if informed consent was required for each disclosure. Doctors consult with each other, specimens are sent to labs, patients are referred for physiotherapy and prescriptions are filled. Patients know this and do not expect to be asked for permission each time something is done for them. A *custodian* may disclose information, without consent, to another *custodian* for the purpose of providing a *health service* to a patient.

Disclosure to Continuing Care Providers

The Act allows disclosure of *health information* to persons responsible for providing continuing treatment and care to an individual. However, it does not define "continuing care provider" because the range of people who provide such services is very broad. Terminally ill or ageing patients are often cared for at home by **family** or by others who are not *custodians*. **Parents** care for younger children. These people often have to give medicine to the patient and often are the source for collecting information about the patient's condition. *Custodians* may disclose information without consent to such people so that they may provide care to the patient. One example would be the provision of a prescription to a third party who is caring for the individual.

Example 13 REQUEST BY CAREGIVERS

Thomas is a 78 year old man with severe emphysema. He is to be discharged after a stay in hospital. His wife, Laura, plans to look after him in their home. She has asked their family physician for information on Thomas' day to day needs.

Can the doctor provide information to Laura?

Laura is Thomas' caregiver, so her request can be answered and the Act provides for disclosure of such information.

Unless the doctor is aware that Thomas does not want the information disclosed, there is no reason to withhold information from Laura.

Example 14 DISCLOSURE OF A CHILD'S COUNSELLING NOTES TO PARENTS

A 14 year-old boy is receiving counselling for behavioural problems. He only agreed to go to counselling if the sessions were kept confidential. He lives with his parents and two younger siblings. The parents want the counsellor to disclose information about the boy's progress and statements made during the counselling sessions.

Can the counsellor disclose information to the parents?

Parents do not have an automatic right to information about their child. If the boy is competent to exercise his rights under the Act, he must be allowed to exercise them. Remember that disclosure may be made to any person if the subject of the information lacks the mental capacity to consent and disclosure would be in their best interest. The counsellor, using his professional judgement, determines that the boy is mature enough to understand his HIA rights.

Disclosure in general terms is allowed to family members (and is discussed further on in this section), but only if the patient has not expressly requested that it not be made. As the boy only went to counselling on the basis that the sessions be confidential, even limited disclosure to the parents would not be allowed.

Example 15 DISCLOSURE OF A CHILD'S COUNSELLING NOTES TO PARENTS

A 16 year-old girl is receiving counselling due to depression. During these sessions she tells the counsellor that she is contemplating suicide. The parents are concerned that their daughter's depression is not improving and have asked the counsellor to disclose information on her progress or any statements revealed during the sessions.

Can the counsellor disclose information to the parents?

Parents do not have an automatic right to information about their children. If they are competent to exercise their rights under the Act, they must be allowed to do so.

However, *custodians* have the discretion to disclose *health information* without consent to any person if they believe that the disclosure will avert or minimize an imminent danger to the health or safety of any person.

Due to the revelations of suicidal thoughts and intentions, the counsellor, in his professional opinion, decides to disclose *health information* to the parents in the belief that it will avert an imminent danger to their daughter.

Health information may be disclosed to avert imminent danger

Disclosure Due to Family/Close Personal Relationship

Disclosure can be made in such cases as long as the patient has not expressly requested that disclosure not be made.

The information that may be disclosed must be in general terms and concern the **presence, location, condition, diagnosis, prognosis and progress of the patient on the day on which the information is disclosed**.

Disclosure can also be made so that family members or a person who has a close personal relationship can be contacted to advise that the patient is injured, ill or deceased.

Determining whether a person who is not a family member has a close personal relationship to the patient is a judgement call. Disclosure to friends is generally not made, but if two people live together or a patient has no family, disclosure to a close friend may be appropriate.

The Act also allows a restricted disclosure to a deceased individual's descendant if the disclosure is necessary for providing a *health service* to the descendant.

Disclosure in Judicial or Quasi-Judicial Proceedings

Sometimes *custodians* are parties (e.g. plaintiffs or defendants) in court or administrative proceedings. *Custodians* may disclose *health information* for the purpose of bringing or defending such actions.

Sometimes *custodians* are not parties to the action at all, but have information in their possession that is needed by the parties or the court to help decide the case. Often the parties to the case exchange information willingly, but sometimes they do not and the court will issue an order or subpoena to require the disclosure of relevant *health information*.

Custodians must comply with such orders, but they should be careful to disclose only the information they are required to disclose.

Disclosure to Preserve Health/Safety

A *custodian* may disclose information **to any person** if he or she believes, on **reasonable grounds**, that the disclosure will avert or minimize an **imminent danger** to the **health or safety** of **any** person.

This can be a difficult section to interpret due to the presence of the word "imminent", which is not defined in the Act. It can mean that a danger is apparent **and** likely to happen very soon.

Disclosure is allowed to preserve health and safety

Example 16	**DISCLOSURE TO LESSEN A SERIOUS AND IMMINENT THREAT**
A doctor has a patient who is employed as a bus driver. The patient has been experiencing bouts of forgetfulness and confusion. The doctor feels the patient may be experiencing early symptoms of Alzheimer's disease. He feels the patient should not be driving, but the patient refuses to stop.	
What can the doctor do?	The doctor must make a judgment call as to whether the danger to passengers, other drivers, pedestrians and even the patient is **imminent**. If it is, the doctor **may inform any person** if the doctor believes that will avert or minimize the danger. This could include disclosure to the patient's employer, the police and the motor vehicle licensing branch. If information were disclosed to the employer in this example, a notice would have to be given to the employer, stating that the information was being disclosed for the purpose of preserving public safety and that the disclosure was authorized by the *Health Information Act*.

DISCLOSURE TO POLICE

Custodians need to consider all applicable provisions under the Act when deciding whether or not to disclose *health information* to police including any expressed wishes that the individual may have.

Disclosure to Police may be classified in three ways:

- with consent;
- without consent; and
- mandatory.

Disclosure to Police with Consent

Custodians are allowed to disclose *health information* to a person other than the individual, when the individual or an individual with the authority to exercise rights on behalf of the individual, has consented to the disclosure.

Disclosure to Police Without Consent

Disclosure **may** be made to the police in the following circumstances:

Family Members

For contacting family members where an individual is injured, ill or deceased.

Subpoenas, Warrants and Court Orders

For purposes of complying with a subpoena, warrant or order issued by a court or other persons or bodies having jurisdiction in Alberta to compel the information.

Imminent Danger

To avert or minimize an imminent danger to the health or safety of any person.

Best Interests

When the individual lacks capacity to provide consent, if in the opinion of the *custodian*, the disclosure is in the best interests of the individual.

Enactments

When the disclosure is authorized or required by an enactment of Alberta or Canada.

Prevent or Limit Fraud or Abuse of Health Services

If the information relates to the possible commission of an offence under a statute or regulation of Alberta or Canada and the disclosure will detect or prevent fraud or limit abuse in the use of *health services*.

This section of the Act allows the disclosure of the following information:

- The name of an individual;
- The date of birth of an individual;
- The *personal health number* of an individual;
- The nature of any injury or illness of an individual;
- The date on which a *health service* was sought or received by an individual;
- The location where an individual sought or received a *health service*;
- The name of any drug, as defined in the *Pharmacy and Drug Act*, provided to or prescribed for an individual and the date the drug was provided or prescribed; and
- Specified information about a *health services provider* who provided a *health service* to an individual.

Disclosure is allowed to avert or minimize an imminent danger to the health or safety of any person

Protect Public Health and Safety

If the *custodian* reasonably believes the information relates to the possible commission of an offence under a statute or regulation of Alberta or Canada and the disclosure will protect the health and safety of Albertans. This section of the Act allows the disclosure of the following information:

- The name of an individual;
- The date of birth of an individual;
- The nature of any injury or illness of an individual;
- The date on which a *health service* was sought or received by an individual;
- The location where an individual sought or received a *health service*;
- Whether any samples of bodily substances were taken from an individual (it should be noted that this **does not** authorize disclosure of the **test results** for samples of bodily substances, but rather only whether bodily samples were taken); and
- Specified information about a *health services provider* who provided a *health service* to an individual.

Example 17 DISCLOSURE TO AVERT OR MINIMIZE AN IMMINENT DANGER

A man presents to the emergency department for treatment after receiving minor injuries from a vehicle accident. While providing care the physician notes that the man's breath smells of alcohol, he has bloodshot eyes and his speech is slurred, and concludes the man is impaired by consumption of alcohol. The man says he intends to drive his vehicle home, and despite the physician's offer to call a taxi, leaves emergency with his car keys in hand.

Does the *custodian* have reasonable grounds to believe disclosure will avert or minimize an imminent danger?	Where a *health services provider* has reasonable grounds to believe disclosure would avert imminent danger, the amount of information necessary to avert the danger may be disclosed. It is reasonable to conclude, when an individual demonstrates they are impaired and intend to drive, that disclosure would avert an imminent danger to other individuals.

Disclosure is allowed to prevent fraud and abuse

Example 18 DISCLOSURE TO PREVENT FRAUD: PRESCRIPTION FRAUD

An individual enters a pharmacy and requests that a prescription for an opioid pain medication be filled. The pharmacist believes the prescription has been altered to increase the number of pills.

What is the police and *custodian's* perspective?

The police perspective is that reporting suspected attempts to fraudulently obtain medication alerts police to a possible offence so an investigation can be conducted. The information may also link to a known drug related issue that is part of a broader police investigation (example, crystal meth investigation).

The *custodian* perspective is that in exercising discretion, the *custodian* will consider disclosure necessary to prevent or detect prescription fraud and balance this interest with the individual's right to confidentiality and professional and ethical obligations.

The *custodian* must answer the following questions:

1. Does the information relate to the possible commission of an offence under a statute or regulation of Alberta or Canada, and
2. Would disclosure prevent fraud or limit abuse in the use of *health services*?

Does the information relate to the possible commission of an offence?

Fraudulently obtaining or attempting to obtain prescription medication is an offence. As a *health services provider* you may encounter an individual attempting to fraudulently obtain medication. Alternatively, police might tell you they are investigating a situation to determine whether an individual is fraudulently obtaining medication. In either case, the *health information* relates to the possible commission of an offence under the *Criminal Code (Canada)*, which is a statute of Canada.

Would disclosure prevent or limit abuse in use of *health services*?

Where an individual is attempting to fraudulently obtain medication, disclosure to police will prevent or limit abuse in the use of *health services* by ensuring funds are only used to pay for medication that has been properly prescribed.

When a *custodian* reasonably believes the answer to both of the above questions is "yes", then the *custodian* has discretion to disclose limited *health information* to police.

Example 19 DISCLOSURE TO PROTECT THE HEALTH OR SAFETY OF ANY PERSON: DOMESTIC VIOLENCE

A husband and wife attend at a walk-in clinic. The wife has a black eye and visible abrasions on her face and hands. The couple's story as to how the wife's injuries occurred is not consistent with the physical evidence. The husband has made it clear that he does not want his wife to talk alone with the clinic staff.

What is the police and *custodian's* perspective?

The police perspective is that if they are notified of injuries that may have been sustained in domestic disputes, they can investigate the specific situation and determine whether they believe that a criminal offence has occurred. If police are involved, they can seek an appropriate opportunity to gather evidence and may be able to speak to the wife alone.

The *custodian* perspective is that reporting to police may impact confidentiality of the patient-doctor relationship. The individual may also express a request that *health information* not be disclosed to police and want to decide for themselves if and or when to talk to the police. Further, in some situations, disclosure to the police may not serve to protect health and safety.

The *custodian* must answer the following questions:

1. Does the information relate to the possible commission of an offence under a statute or regulation of Alberta or Canada, and
2. Will the disclosure protect the health and safety of Albertans?

Does the information relate to the possible commission of an offence?

A physical injury that results from a domestic dispute is a criminal offence. As a *custodian* you may already know from the circumstances that physical injuries have been sustained that relate to a domestic dispute and assault, which means that there has been the possible commission of a criminal offence. Alternatively, police might tell you that they are investigating the situation to determine whether a criminal offence has occurred. The *health information* relates to the possible commission of an offence under the *Criminal Code (Canada)*, which is a statute of Canada.

Would disclosure protect public safety?

Where physical injuries have been sustained by a spouse in a domestic dispute, disclosure to police may protect the health and safety of the injured spouse. However, in some situations, disclosure could also increase the risk of harm. In the case of a domestic dispute a *custodian* will need to carefully consider all facts, and in particular

Example 19 (con't) **DISCLOSURE TO PROTECT THE HEALTH OR SAFETY OF ANY PERSON: DOMESTIC VIOLENCE**

the patient's express request, before deciding whether disclosure will protect health and safety. When the disclosure of *health information* will protect the health and safety of the individual, other individuals or the public of Alberta, then the disclosure will protect the health and safety of Albertans.

When a *custodian* reasonably believes the answer to both of the above questions is "yes", the *custodian* has discretion to disclose limited *health information* to police. In situations where disclosure may increase the risk of harm, the answer to the second question is "no" and therefore *health information* should not be disclosed.

Mandatory Disclosure

Although the HIA does not contain a mandatory disclosure to police provision, it is important to be aware of the *Gunshot and Stab Wound Mandatory Disclosure Act*.

This Act requires health care facilities and emergency medical technicians who treat gunshot or stab wounds to disclose *health information*, without consent, to the police. Therefore, this is an example of disclosure without consent that is authorized or required by an enactment of Alberta.

Disclosure under the enactment: *Gunshot and Stab Wound Mandatory Disclosure Act* requires the following health information to be disclosed to the police:

- The injured person's name, if known;
- Whether the injury was a gunshot or stab wound;
- In the case of a health care facility, the name and location of the health care facility;
- In the case of an emergency medical technician, the location attended to treat the injured person; and
- Any other information that may be required by the regulations.

Example 20	**STABBINGS AND SHOOTINGS**
An individual has sustained a stab or gunshot wound and goes to the emergency department of a hospital for *health services*.	
Should a *custodian* disclose information about a stab or gunshot wound?	Health Care facilities and emergency medical technicians have an obligation to report gunshot or stab wounds to a police service under the *Gunshot and Stab Wound Mandatory Disclosure Act*, therefore, limited *health information*, as outlined in that Act, must be provided to the police for their investigation.

Disclosure to a Health Information Repository

The Act allows disclosure of *health information* to a *health information repository*. The Minister may designate, by regulation, an agency, corporation or other entity to act as a *health information repository*. Powers, duties and functions of a *health information repository* will be in accordance with the regulations.

Disclosure for Research Purposes

The Act contains provisions that expressly govern the disclosure of *health information* for research purposes. These provisions require the submission of a proposal to a *research ethics board* (REB). If the REB approves the proposal, the researcher may ask a *custodian* to disclose information, but **the *custodian* does not have to disclose the information**. If the *custodian* chooses to disclose the information, an agreement outlining the REB's conditions and any conditions imposed by the *custodian*, as well as terms protecting the information and the identities of the persons involved in the research, must be signed.

RIGHT OF ACCESS TO HEALTH INFORMATION

General

Right to access is not unrestricted

A person has a right of access to any ***record*** that contains *health information* **about that person** that is in a *custodian's* **custody or control**. If a *record* is not in the *custodian's* hands, but the *custodian* has the power to retrieve it, then the *record* is in the *custodian's* control. You may have sent a file to storage, but if you can retrieve it, the *record* is still in your control. In the world of electronic *records* where the *custodian* may only have control but not custody, the *custodian* is still responsible to handle an access request. In the case of the Alberta EHR, any *custodian* participating in the Alberta EHR is responsible for handling access requests.

People do not have an unrestricted right of access, as *custodians* are allowed to refuse or may be required to refuse access in certain situations. The Act gives people a right to access their *health information*, but not the right to have the original documents. **Partial access** may be available if a *custodian* has grounds for not disclosing some information. In such cases, the information that is not disclosed should be severed from the *record* with the remainder of the *record* being disclosed.

Custodians **may** charge specified fees for giving access (see the section on fees). The right of access is generally subject to the payment of the fee.

Remember that you have a duty to make a reasonable effort to ensure that the information is disclosed to the person intended and authorized to receive it. If you are a *custodian* that does not know the applicant personally, you should get proper identification before releasing the information.

What is a Record?

The Act is very specific about what a *record* is. Obvious *records* are such things as notes, letters, documents and x-rays. Any *health information* that is **written, photographed, recorded or stored in any manner** is a *record*. Even if information is only stored on your computer, it is contained in a *record*. If a hard copy of a *record* does not exist, but can be created from information that is in electronic form by using your normal computer hardware and software and technical expertise, then you must create a hard copy of the *record* if an individual requests it. You do not have to do this if creating the *record* would unreasonably interfere with your operations.

Requests for Access

The Act does not require that you change your current practices for release of information. However, your procedures must be in compliance with the *Health Information Act*.

A person who makes a request for access under HIA can ask for a **copy of the *record*** or to **examine the *record***. A *custodian* may require the person to make the request in writing, and may request **further information** from that person to clarify the scope of the request. The *custodian* must make every **reasonable effort to respond within 30 days** of receiving the request. People do not have to explain why they want their *health information*.

Requests can be abandoned. If a *custodian* requests that a person pay a fee or supply further information and the person doesn't respond, the *custodian* may notify the person in writing that the request has been abandoned. The written notice must also advise the person that he/she can ask the *Commissioner* for a review of the *custodian's* decision.

In some cases a request may be for access to a *record* that contains non-health related information to which another Act such as the *Freedom of Information and Protection of Privacy Act* (FOIP) applies. If you are a *custodian* that is also a public body under FOIP, e.g. a public hospital, you must treat that part of the request as a request under FOIP and the provisions of FOIP apply to that part of the request.

Responding to Requests – What You Must Do

Custodians must make every **reasonable effort to assist applicants** and to **respond openly, accurately** and **completely**. You must, where it is **reasonably practicable**, explain any term, code or abbreviation used in the *record* if the applicant requests it.

Remember that, where practical, you must **create a *record*** if an individual requests it.

You must make every **reasonable effort to respond within 30 days** of receiving the request. It is possible to **extend this period** for an additional 30 days, without *Commissioner* approval, for the following reasons:

- if the request for access is not detailed enough for you to identify the *record*;
- if a large number of *records* are involved; or
- if you must consult with another *custodian* to determine whether access should be given.

Custodians must assist people seeking access

With any time extension you must:

- give the applicant the reason for the extension;
- tell them when a response can be expected; and
- advise them that they may make a complaint to the *Commissioner*.

If you do not respond within the required time, you are deemed to have refused access to the applicant.

You must tell the applicant:

- whether you will give access to all or part of the *record*; and
- where, when and how access will be given, if it is to be given.

If access to all or part of the *record* is refused you must tell the applicant:

- the reason(s) for the refusal and the provision(s) of the Act you relied on for refusing to give access;
- the name, title, business address and phone number of an *affiliate* who can answer questions about the refusal; and
- that the applicant may ask the *Commissioner* to review the decision to refuse access.

You Must Refuse Access

A *custodian* **must** refuse access in a number of situations.

The ones most likely to arise are:

- where the request is for access to information about a person **other than the applicant** (unless the information was provided by the applicant in the first place in the context of a *health service* being provided to the applicant);
- where disclosure is prohibited by another law of Alberta; or
- where the information sets out procedures or contains results of an investigation, discipline proceeding, practice review or an inspection relating to a *health services provider*.

You May Refuse Access

Sever information that should not be disclosed

A *custodian* **may** refuse to allow access in a number of situations.

The ones most likely to arise are where the disclosure could reasonably:

- be expected to result in **immediate and grave harm to the applicant's mental or physical health or safety;**
- be expected to **threaten the mental or physical health or safety of another individual;**
- be expected to pose a threat to public safety; or
- lead to the identification of a person who provided *health information* to the *custodian* explicitly or implicitly **in confidence** and in circumstances in which it was appropriate that the person's name be kept **confidential**.

Remember that if you can **sever** information to allow **partial access** you must do so.

Example 21

DISCRETIONARY REFUSAL OF ACCESS DUE TO A THREAT TO THE SAFETY OF ANOTHER INDIVIDUAL

Sue's husband has physically abused her on many occasions. After the last episode the husband was convicted of assault and ordered to take a regional health authority sponsored anger management program and stay away from Sue. Sue has since left her husband and now lives alone, but her husband suspects she is "having an affair". Sue tells a friend that her husband is stalking her and on a number of recent occasions the friend has observed the husband following Sue. Sue and her friend report this to the husband's psychiatrist who makes a note of it on the husband's case file, as it indicates the mental health state of the husband. The psychiatrist raises the issue at the husband's next counselling session. The husband demands to know who told the psychiatrist he has been following his wife. The husband demands access to the psychiatrist's notes about himself.

Can the psychiatrist refuse to provide access to his notes?	It is clear the husband is an abusive individual and could pose a danger to Sue and her friend. The psychiatrist could refuse to give access to the parts of his notes that reference the report by Sue and her friend on the basis that they gave the information to the counsellor on the condition that it would be kept confidential, or that release would be a threat to the safety of another individual.

Example 22	HEALTH & SAFETY
Rita is an elderly patient with bipolar disorder and a number of other physical ailments that require her to be in regular contact with her doctor and frequent admissions to the hospital. Rita has never accepted the diagnosis of bipolar disorder and becomes very agitated and distressed when it is discussed. She is unreliable about taking her medication and needs monitoring. Rita has asked the hospital for access to her *records*.	
Should the hospital allow Rita access to her medical *records*?	The hospital has reservations about releasing them because they make reference to her bipolar disorder and contain family and friends names who have participated in case conferences. The hospital has discussed the matter with Rita's doctor. The doctor believes disclosure may compromise Rita's health, mentally and possibly physically as her compliance with treatment has been sporadic. There also exists the possibility that if Rita were to find out the names of individuals who provided information about her during case conferences, that she could pose a physical threat to them based on her past behavioural patterns when she is ill. Under these circumstances access should probably not be granted. However, the hospital must decide if access could reasonably be expected to result in immediate and grave harm. The mental distress would be immediate, but is it grave? It is arguable whether the mental problems that could result from her withdrawal of medications could be classified as either an immediate or grave danger to herself or others. The hospital should consider whether it is possible to **sever** references to the information that may be harmful, including names and then disclose the rest of her *records*.

Fees

The Act allows *custodians* to charge fees for providing access to *records*. The services for which fees **may** be charged and the amount that may be charged are specified in the regulations. Only these fees, as set out in the regulations can be charged.

Custodians must **give an estimate** of the total fees that will be charged before providing the services. The regulations specify what must be set out in an estimate.

Custodians have the **discretion to excuse an applicant from paying all or part of the fees**. If an applicant asks to be excused from paying all or part of a fee and the *custodian* refuses, the *custodian* must tell the applicant that they can have that decision reviewed by the *Commissioner.*

CORRECTING OR AMENDING HEALTH INFORMATION

General

A person who believes that his or her *health information* contains an **error or omission** may request that the *custodian* who has **custody or control** of that information correct or amend it. The request must be **in writing**.

Patients can ask for health information to be corrected

Remember that *custodians* have a **duty** to ensure that *health information* is **accurate** and **complete**.

As with requests for access, the *custodian* has **30 days** to make the correction or amendment, although **that period may be extended**.

If the *custodian* agrees to make the change or amendment, the *custodian* must give the applicant **written notice** that the correction or amendment has been made and **notify** any person and/or *health information repository* to whom the information has been disclosed (in the last year before the correction or amendment was requested) that the change has been made. **This notice does not have to be given** if the *custodian* believes that not giving notice will not harm the applicant and the applicant agrees with this decision.

A *custodian* may refuse to make a correction or amendment of a professional opinion or observation made by a *health services provider* about the applicant, or of a *record* that was not originally created by the *custodian*.

Where a patient disagrees with a diagnosis that later proves to have been incorrect, you should attach a statement correcting the earlier diagnosis and notify anybody to whom the information was previously disclosed. Removing all reference to the earlier diagnosis could make the *record* incomplete, as there would be nothing to explain any treatment that was given on the basis of that diagnosis.

If the *custodian* fails to respond to a request it is **deemed to have refused** to make the correction or amendment.

If the *custodian* refuses to make the correction or amendment, the *custodian* must, within the thirty-day period (or during the extended period), tell the applicant of the refusal to correct or amend and **give the reasons for refusing**.

A *custodian* who refuses to make a requested change or amendment must also **advise the applicant** that he or she may do one of two things:

- ask the *Commissioner* to **review** the *custodian's* decision; **or**
- submit a **statement of disagreement** setting out the requested change or amendment and their reasons for disagreeing with the *custodian's* decision not to make the change or amendment.

If a statement of disagreement is submitted the *custodian* **must** attach it to the *record* (if reasonably practicable) and send the statement to any person to whom the *custodian* has disclosed the *record* in the year preceding the request for the change or amendment.

In respect to notifying *health information repositories* that a change or amendment has been made, the *custodian* must also advise the repository how the *health information* must be corrected or amended. *Health information repositories* who have been notified about making a correction or amendment have 30 days to make the correction or amendment according to the advice of the *custodian* and to notify the *custodian* that the correction and/or amendment has been made. It is the *custodian's* responsibility to notify the individual who made the request that the *health information repository* has made the change.

An individual may ask the *Commissioner* to review:

- a failure of a *custodian* to notify a *health information repository* of a correction or amendment; or
- a failure by the *health information repository* to make the correction or amendment.

Example 23

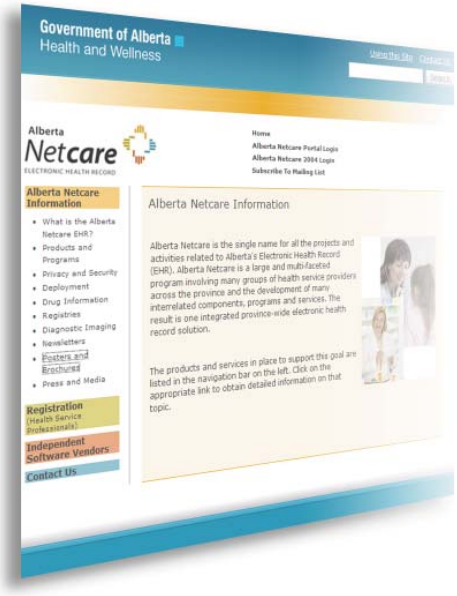
CORRECTING A DISPUTED DIAGNOSIS

A patient presents with an unexplained illness at a hospital. A diagnosis of acute anxiety attack is made, and a course of psychiatric counselling is recommended. The patient consults an independent psychiatrist who renders a different diagnosis. The patient requests that the hospital remove the reference to the diagnosis from the hospital *records*. The hospital refuses to do so because it represents a clinical opinion and the subsequent course of treatment provided to the patient based on that clinical opinion.

What options does the patient have?	The *custodian* must advise the patient that they can ask the *Commissioner* to review the *custodian's* decision; **or** Submit a statement of disagreement of 500 words or less to be attached to the chart reflecting the independent psychiatrist's diagnosis.

Alberta Electronic Health Record

General



Alberta has developed the ability for *custodians* to access and share *health information* electronically, in a secure way. The majority of *custodians* manage their *health information* through electronic *record* systems. It is via these systems that *custodians* allow *health information* under their custody or control to be made available and shared through the *Alberta Electronic Health Record*, also known as **Alberta Netcare**.

What is the Alberta Electronic Health Record?

The Act defines the *Alberta Electronic Health Record* (*Alberta EHR*) as the integrated *health information* system established to provide shared access by authorized *custodians*, such as Alberta Health Services, the Minister and the Department, and independent *health services providers,* to prescribed *health information* in a secure environment. The Act states that making prescribed *health information* available through the *Alberta EHR* is considered a use and not a disclosure of *health information.* The Act also says that accessing information through the *Alberta EHR* is considered a use and not a collection of *health information.*

Management of the Alberta EHR

Alberta Health and Wellness is currently designated the *information manager* of the *Alberta EHR*. There is also a multi-disciplinary data stewardship committee which establishes rules with respect to access, use, disclosure and retention of prescribed *health information* via the *Alberta EHR*. These rules are set out within the Information Exchange Protocol (IEP), which all participating *custodians* must follow.

Custodians wishing to become participants in the *Alberta EHR* (known as an authorized *custodian*) must meet certain eligibility requirements as set out in the regulation.

Role of Health Professional Bodies

Health Professional bodies of regulated health professionals have a key role in supporting the operation of the *Alberta EHR*, which is set out in the HIA regulation, as follows:

- Develop and maintain Standards of Practice concerning their regulated members obligation to implement policies and procedures and reasonable safeguards to protect electronic health *records* and to comply with the Act; and
- Direct their regulated members as to what "*prescribed health information*" to make accessible via the *Alberta EHR*.

Submission of Health Information to the Alberta EHR

In general, the health professional bodies of regulated health professionals direct their members as to what "*prescribed health information*" to make accessible via the *Alberta EHR*.

A health professional body may decide not to direct its regulated members to make *health information* accessible via the *Alberta EHR*, or may choose not to direct its members to make available what the Minister determines is in the public interest to be made accessible. In this case, the Minister may direct the regulated health professionals to make the prescribed *health information* accessible via the *Alberta EHR*.

Before the Minister gives such a direction, the Minister must;

- consult with the health professional body;
- prepare a privacy impact assessment and submit it to the *Commissioner* for review and comment; and
- consider the comments, if any, of the *Commissioner*.

Health information may be masked and hidden from view in the Alberta EHR.

Express Wishes of Individuals Apply

Custodians must consider any expressed wishes of the individual about the access or use of their *health information* through the *Alberta EHR*. If an individual makes an express wish to limit their *health information* from being accessed, it is possible to honour such a request via masking of their *health information* in the *Alberta EHR*. Masking means that certain information is hidden from view from most users who may view the individual's electronic *record.* The *record* may be unmasked by an authorized *custodian* to provide care. **The *Alberta EHR* keeps a log of all unmasking decisions.** *Custodians* with questions about how to implement masking should contact Alberta Health and Wellness, the *information manager* for the *Alberta EHR*.

Authorized Use of the Alberta EHR

Some *custodians,* such as Alberta Health Services, Alberta Health and Wellness and the Minister are named in the Act as *custodians*. These *custodians* may use the *Alberta EHR* for all of the uses described in the previous section "Using *Health Information*" in this guide, as long as those uses comply with the information exchange rules set out within the Information Exchange Protocol.

Other *custodians* that meet the eligibility requirements set in regulation may also be considered "authorized *custodians*", and may only use the prescribed *health information* in the *Alberta EHR* for:

- providing a *health service*;
- determining or verifying a person's eligibility to receive a *health service*; or
- carrying out any purpose set out in the IEP that is an authorized use under the HIA.

Maintaining a Record of the Alberta EHR

Authorized *custodians* who use prescribed *health information* via the *Alberta EHR* must keep an electronic log containing:

- user and application identification associated with an access;
- name of user and application that performs an access;
- date of an access;
- time of an access;
- actions performed by a user during an access, including, without limitation, creating, viewing, editing and deleting information;
- name of facility or organization at which an access is performed;
- display screen number or reference;
- *personal health number* of the individual in respect of whom an access is performed; and
- and other information required by the Minister.

This functional requirement is performed by Alberta Health and Wellness as they are the designated information manager for the *Alberta EHR*. The log must be kept for 10 years following the date of the use.

The information manager of the *Alberta EHR* must conduct an audit each month of the access logs of the *Alberta EHR*. Such an audit allows for an examination of use of the *Alberta EHR* to reasonably ensure it is being used in compliance with the Act.

It is important to note that the *Alberta EHR Regulation* also defines a *custodian's* logging requirements for implementation of a new, or where significant changes are being made to an existing, electronic health *record* system. These logging requirements parallel the requirements for the *Alberta EHR,* that are set out above.

Access Rights of Individuals Apply

Individuals may request a copy of the log that shows who has accessed their record in the Alberta EHR.

Access rights of individuals apply to the *Alberta EHR*, therefore, individuals may make a request to any *custodian* participating in the *Alberta EHR* for access to, or a copy of their *health information*. In addition, individuals may request a copy of the log identifying who has accessed their *health information* from the information manager of the *Alberta EHR* or from any participating *custodian*.

The HIA's usual rules for processing access requests apply to an access request for *health information* and for logs from the *Alberta EHR*. See Chapter 9 for details on the right to access *health information*.

Correction Rights of Individuals Apply

Correction or amendment rights apply to the Alberta EHR. Therefore, individuals may make a request to any *custodian* participating in the Alberta EHR to make a correction or amendment to their *health information*. The HIA's usual rules for processing a correction or amendment request apply. Refer to Chapter 10 for details on correcting or amending *health information*.

ROLE OF THE COMMISSIONER

General

The *Commissioner* is the **Information and Privacy Commissioner** appointed under the *Freedom of Information and Protection of Privacy Act*.

Office of the Information and Privacy Commissioner of Alberta

The *Commissioner* is **independent from government** and has the power to review the conduct of *custodians* and any *health information repository*.

The Commissioner is independent and impartial

Reviews by the Commissioner

In particular the *Commissioner* may review:

- any decision, act or failure to act by a *custodian* who has been asked to give access to or correct or amend a *record* by the person who is the subject of the *record*;
- a claim by an individual that his or her *health information* has been improperly collected, used or disclosed; and
- a decision by one *custodian* to refuse to disclose information to Alberta Health Services when Alberta Health Services paid for the service.

A person must give a **written request** to the *Commissioner* in order to ask **for a review**. The *Commissioner* may authorize a mediator to investigate and attempt to settle a dispute, but if it cannot be settled the *Commissioner* may conduct an inquiry and make an order disposing of the issues.

The *Commissioner* **may also investigate** and attempt to resolve **complaints** that:

- a duty to assist a person who has applied for access has not been performed;
- there has been an improper extension of time for responding to a request;
- a fee charged under the Act is inappropriate;
- a correction or amendment of *health information* has been improperly refused; or
- a *custodian* has improperly collected, used, disclosed or created *health information*.

Monitoring of the Act

The *Commissioner* is generally responsible for monitoring how this Act is administered and may:

- conduct investigations to ensure compliance with the Act;
- inform the public about the Act;
- receive comments from the public about the Act;
- comment on privacy impact assessments; and
- exchange information with another provincial or federal commissioner to handle complaints involving two or more jurisdictions.

Whistleblower Protection

An *affiliate*, acting in good faith, may tell the *Commissioner* about any *health information* that the *affiliate* believes is being collected, used or disclosed by a *custodian* in contravention of the Act.

The *Commissioner* **must investigate** and review such allegations and may not disclose the identity of the *affiliate* without his or her consent.

No *custodian* or person acting on the *custodian's* behalf may do anything such as fire or discipline an *affiliate* for disclosing information to the *Commissioner.*

CONCLUSION

The *Health Information Act* is an additional piece of legislation in an existing framework of legal and ethical standards that are used in the day to day management of those needing care and treatment. Understanding the Act will assist in making sense of the larger framework. Common sense is perhaps the best entry point to understanding the Act. If an interpretation of the Act seems to lead to a strange result, it may not be correct.

If guidance is needed on specific issues, *custodians* can call the *Office of the Information and Privacy Commissioner* at 780-422-6860.

Comments on the guide are welcomed.

Please direct them to:

Office of the
Information and Privacy
Commissioner of Alberta
#410, 9925 – 109 St.
Edmonton, AB
T5K 2J8

GLOSSARY

Affiliate - in relation to a custodian

(i) an individual employed by the custodian,

(ii) a person who performs a service for the custodian as an appointee, volunteer or student or under a contract or agency relationship with the custodian,

(iii) a health services provider who is exercising the right to admit and treat patients at a hospital as defined in the *Hospitals Act,*

(iv) an information manager as defined in section 66(1), and

(v) a person who is designated under the regulations to be an affiliate, but does not include

(vi) an agent as defined in the *Health Insurance Premiums Act*, or

(vii) a health information repository other than a health information repository that is designated in the regulations as an affiliate;

Alberta EHR

the integrated electronic health information system established to provide shared access by authorized custodians to prescribed health information in a secure environment as may be further defined in the regulations.

Authorized Custodian

(i) a custodian referred to in section 1(1)(f)(iii), (iv), (vii), (xii) or (xiii), other than the Health Quality Council of Alberta, and

(ii) any other custodian that meets the eligibility requirements of the regulations to be an authorized custodian.

Collect

to gather, acquire, receive or obtain health information;

Commissioner

the Information and Privacy Commissioner appointed under Part 4 of the *Freedom of Information and Protection of Privacy Act*;

Custodian

(i) the board of an approved hospital as defined in the *Hospitals Act* other than an approved hospital that is

(A) owned and operated by a regional health authority established under the *Regional Health Authorities* Act, or

(B) repealed 2008 cH-4.3 s18;

(ii) the operator of a nursing home as defined in the *Nursing Homes Act* other than a nursing home that is owned and operated by a regional health authority established under the *Regional Health Authorities Act*;

Custodian (con't)

(ii.1) an ambulance operator as defined in the *Emergency Health Services Act*;

(iii) a provincial health board established pursuant to regulations made under section 17(1)(a) of the *Regional Health Authorities Act*;

(ii) the operator of a nursing home as defined in the *Nursing Homes Act* other than a nursing home that is owned and operated by a regional health authority established under the *Regional Health Authorities Act*;

(iv) a regional health authority established under the *Regional Health Authorities Act*;

(v) a community health council as defined in the *Regional Health Authorities Act*;

(vi) a subsidiary health corporation as defined in the *Regional Health Authorities Act*;

(vii) repealed 2008 cH-5.3 s18;

(viii) a board, council, committee, commission, panel or agency that is created by a custodian referred to in subclauses (i) to (vii), if all or a majority of its members are appointed by, or on behalf of, that custodian, but does not include a committee that has as its primary purpose the carrying out of quality assurance activities within the meaning of section 9 of the *Alberta Evidence Act*;

(ix) a health services provider who is designated in the regulations as a custodian, or who is within a class of health services providers that is designated in the regulations for the purpose of this subclause;

(x) a licensed pharmacy as defined in the *Pharmacy and Drug Act*;

(xi) repealed;

(xii) the Department;

(xiii) the Minister;

(xiv) an individual or board, council, committee, commission, panel, agency, corporation or other entity designated in the regulations as a custodian;

Custodian (con't)

but does not include:

(xv) repealed 2008 cH-4.3 s18;

(xvi) a Community Board as that term is defined in the *Persons with Developmental Disabilities Community Governance Act* other than a Community Board that is designated in the regulations as a custodian;

Diagnostic, Treatment & Care Information

Information about any of the following:

(i) the physical and mental health of an individual;

(ii) a health service provided to an individual, including the following information respecting a health services provider who provides a health service to that individual:

- (A) name;
- (B) business title;
- (C) business mailing address and business electronic address;
- (D) business telephone number and business facsimile number;
- (E) type of health services provider;
- (F) licence number or any other number assigned to the health services provider by a health professional body to identify that health services provider;
- (G) profession;
- (H) job classification;
- (I) employer;
- (J) municipality in which the health services provider's practice is located;
- (K) provincial service provider identification number that is assigned to the health services provider by the Minister to identify the health services provider;
- (L) any other information specified in the regulations;

(iii) the donation by an individual of a body part or bodily substance, including information derived from the testing or examination of a body part or bodily substance;

(iv) a drug as defined in the *Pharmacy and Drug Act* provided to an individual;

(v) a health care aid, device, product, equipment or other item provided to an individual pursuant to a prescription or other authorization;

Diagnostic, Treatment & Care Information (con't)

(vi) the amount of any benefit paid or payable under the *Alberta Health Care Insurance Act* or any other amount paid or payable in respect of a health service provided to an individual,

and includes any other information about an individual that is collected when a health service is provided to the individual, but does not include information that is not written, photographed, recorded or stored in some manner in a record.

Health Information

Any or all of the following:
(i) diagnostic, treatment and care information;

(ii) registration information

Health Information Repository

An agency, corporation or other entity designated by the Minister to act as a health information repository in accordance with part 6.1

Health Service

A service that is provided to an individual for any of the following purposes:
(i) protecting, promoting or maintaining physical and mental health;

(ii) preventing illness;

(iii) diagnosing and treating illness;

(iv) rehabilitation;

(v) caring for the health needs of the ill, disabled injured or dying;

but does not include a service excluded by the regulations.

Health Services Provider

An individual who provides health services.

Individually Identifying

When used to describe health information, means that the identity of the individual who is the subject of the information can be readily ascertained from the information.

Non-Identifying

When used to describe health information, means that the identity of the individual who is the subject of the information cannot be readily ascertained from the information.

Personal Health Number

The number assigned to an individual by the Department to uniquely identify the individual.

Record

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

Research Ethics Board

A body designated by the regulations as a research ethics board.

Registration Information

Information relating to an individual that falls within the following general categories and is more specifically described in the regulations:

(i) demographic information, including the individuals personal health number;

(ii) location information;

(iii) telecommunications information;

(iv) residency information;

(v) health service eligibility information;

(vi) billing information;

but does not include information that is not written, photographed, recorded or stored in some manner in a record.

Use

To apply health information for a purpose and includes reproducing information, but does not include disclosing information.

NOTES

NOTES

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Information and Privacy
Commissioner of Alberta

410, 9925 - 109 Sreet
Edmonton, Alberta T5K 2J8
Phone: 780.422.6860
Fax: 780.422.5682

www.OIPC.ab.ca